Defining the prevalence of subjects at ultra high risk of developing psychosis in the general population

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DEFINING THE PREVALENCE OF SUBJECTS AT ULTRA HIGH RISK OF DEVELOPING PSYCHOSIS IN THE GENERAL POPULATION

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ABSTRACT

Current understanding of ultra high risk syndromes for psychosis (UHR) has been based almost entirely on studies of clinical help-seeking populations. The current study aimed to estimate what proportion of the community would meet UHR criteria, to assess whether this was associated with a need for care, and to explore how these individuals relate to those in clinical settings.

An epidemiological sample of 208 young adults (aged 18 to 35) was interviewed using the CAARMS (for positive and negative symptoms) and the SPI-A (for basic symptoms), along with measures of functioning and general psychopathology. Help-seeking was measured in relation to both clinical and informal sources of help. Comparisons were also made with a clinical UHR sample from the OASIS service in South London.

Thirty individuals met symptomatic criteria for an UHR state (14 met CAARMS criteria, 12 met SPI-A criteria, 4 met both), giving an estimated community prevalence of around 13%. Of these, 66% (n = 20) reported an unmet need for care, 52% (n = 15) had sought some form of help and 33% (n = 9) had engaged in clinical help-seeking. Help-seeking and distress were most associated with negative symptoms and least associated with basic symptoms. Nevertheless, these community UHR subjects were less functionally impaired [$t(63) = 3.30$, $p = .003$] and had less severe positive [$z = -4.21$, $p < .001$], negative [$z = -2.63$, $p = .017$] and general psychopathology [$z = -2.74$, $p = .019$] than those already attending clinical services.

Results suggest that the UHR criteria can identify something clinically meaningful even in the general population, and that there may currently be individuals who would benefit from outreach by existing UHR services. However, results also suggest that the current focus on positive symptoms may be insufficient for identifying those in need of care.

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LIST OF ABBREVIATIONS

ALSPAC	Avon Longitudinal Study of Parent and Children
ANS	Attenuated negative symptoms
APS	Attenuated positive symptoms
BEAR	Bern Epidemiological At-Risk study
BLIPS	Brief limited intermittent psychosis
BS	Basic symptoms
BSABS	Bonn Scale for the Assessment of Basic Symptoms
CAARMS	Comprehensive Assessment for the At-risk Mental State
CANSAS	Camberwell Assessment of Need Short Appraisal Scale
CAPE	Community Assessment of Psychotic Experiences
CAPsy	Childhood Adversity and Psychosis study
CEQ	Cannabis Experience Questionnaire
CIS-R	Clinical Interview Schedule - revised
CMD	Common mental disorder
COGDIS	Cognitive disturbance Basic Symptom criteria
COPER	Cognitive-perceptive Basic Symptom criteria
COPS	Criteria of Prodromal Symptoms
CTQ	Childhood Trauma Questionnaire
DSM-IV / DSM-5	Diagnostic and Statistical Manual of Mental Disorders (4^{th} / 5^{th} edition)
EU-GEI	European Network of Schizophrenia Networks for the Study of Gene-Environment Interactions
FIGS	Family Interview for Genetic Studies
GAF-F	Global Assessment of Functioning – (social, interpersonal and occupational) functioning
GAF-S	Global Assessment of Functioning – (psychological functioning and global) symptom level
GRD	Genetic risk and decline
HAM-A	Hamilton's Anxiety scale
HAM-D	Hamilton's Depression scale
ICD-10 / ICD-11	World Health Organisation's International Classification of Diseases (10^{th} / 11^{th} edition)

NEMESIS	Netherlands Mental Health Survey and Incidence Study
OASIS	Outreach and Support in South London
ONS	UK Office of National Statistics
PACE	Personal Assessment and Crises Evaluation clinic
PAF	Postal address file
PE	Psychotic experiences
PSQ	Psychosis screening questionnaire
SCID II	Structured Clinical Interview for DSM-IV – Axis II disorders
SELCoH	Biomedical Research Centre South East London Community Health study
SF-12	12-item Short Form questionnaire
SIPS	Structured Interview for Prodromal Symptoms
SPI-A / SPIA-9	Schizophrenia Proneness Instrument for Adults / (nine-item version)
UHR	Ultra high risk (for psychosis)
WAIS	Wechsler Adult Intelligence Scale

I. INTRODUCTION

CHAPTER 1 THESIS OVERVIEW

This thesis attempts to address the issue of *defining the prevalence of subjects at ultra high risk of developing psychosis in the general population*. Practically, there are two primary components to this. Firstly, a clear definition is needed for determining when someone is at 'ultra high risk' (UHR) for psychosis. Secondly, to estimate the prevalence in the general population, it is necessary to obtain a representative general population sample. These alone are no easy task. However, there are further conceptual issues. Almost everything we know about the UHR state is borne out of research in clinical settings, so what it would mean to meet UHR criteria in the general population, or how individuals identified in this way would compare to those who present to clinical services, is also unclear. This thesis provides some of the important first steps towards understanding these issues.

I start by providing an introduction to the ultra high risk state in Chapter 1, outlining the important concepts and discussing some of the debates and gaps in our understanding. Next, I look at how psychotic experiences have been investigated in the general population, reviewing some of the most important literature and highlighting what it can and cannot tell us about the UHR state. Finally I provide a critical summary and discussion of the few studies which have specifically attempted to do something similar to what is attempted in this thesis, drawing particular attention to why the issue is important, which aspects have not yet been adequately addressed and where there is room for further contribution.

In Chapter 2, I take some of the ideas discussed in the Introduction and apply them to a large general population sample from the South London area. The aim of this chapter is to build on previous work and explore what it is that makes psychotic experiences problematic. To this end, I specifically test the hypothesis that the presence of common mental disorder may distinguish harmless experiences from those which are associated with help-seeking, functional impairment and even suicidality. I also use these data to explore the overlap between symptoms and to generate hypotheses for my main study.

The next section documents the methodology used in the present study. Chapters 4, 5 and 6 outline aspects related to the study design, assessments and handling of data respectively. This is followed by my first Results chapter, which presents the characteristics of the study sample that was recruited, comparing it to census data for the local population area in order to assess its representativeness.

In Chapter 8, I use this sample to estimate the prevalence of the UHR state, based on two main sets of criteria used in clinical population. I also assess the presence of negative symptoms and general psychopathology, and test the relationship between these symptoms and several known correlates of psychotic disorder. In order to understand whether these symptoms in the community have any clinical or pathological relevance, in Chapter 9 I explore associations with distress, impairment, need for care and help-seeking behaviours. I also look specifically at which symptoms are more likely to lead to help-seeking within this group than others. Finally, having explored differences between those who do and do not meet UHR criteria in the general population, in Chapter 10 I explore similarities and differences between the individuals I have identified and a clinical sample of patients who are currently seeking help from the specialist UHR service which serves the same catchment area. I pay particular attention to symptomatic and functional profiles of the groups, assessing what type of differences may be present and considering what this might tell us about the UHR criteria and about the help-seeking process.

I finish with an overall discussion of the issues that have been raised in this thesis and consider the meaning and context of my findings. In particular I highlight the methodological challenges of attempting such a task and the resulting limitations within the bounds of which the results can be interpreted. Finally, I discuss potential clinical implications for the local UHR service and others across the world, and highlight the need for future studies to carry out longitudinal follow-ups of these individuals, in order to investigate the long term consequence of being at 'ultra high risk' for psychosis in the general population.

CHAPTER 2 BACKGROUND AND AIMS

In the last two decades there has been increasing research interest in the early stages of psychosis. Specifically, there has been extensive research on the definition, identification and treatment of individuals presenting with potentially prodromal symptoms, who may be at high risk of developing psychosis within the near future. The aim of this chapter is to introduce and define the key concepts of this thesis and to provide a concise review of the literature most relevant to *defining the prevalence of subjects at ultra high risk of developing psychosis in the general population*, the title of my thesis. To approach this, I will firstly provide a brief introduction to the psychosis prodrome and the ultra high risk (UHR) approach, giving an overview of how the UHR state has been defined, assessed and researched within clinical settings. Secondly, I will review epidemiological research into psychotic experiences in the general population, introducing the concept of a psychosis continuum and discussing the implications that this work may have for the UHR approach. Thirdly, I will critically review the past literature that has attempted to define the general population prevalence of the UHR state to date. Finally, I will conclude this introduction and background chapter by outlining the aims of the present thesis.

2.1 The psychosis prodrome and the ultra high risk (UHR) concept

The onset of psychosis is often preceded by a period of nonspecific morbidity, known as the psychosis prodrome. Some evidence for this comes from studies that have examined the mode of onset in schizophrenia and other psychotic disorders. For example, the World Health Organisation 10-country study found that while 36% of psychotic disorder has an acute onset (within one week), 18% of patients developed symptoms within one month and 40% did so over several months or years (Jablensky et al., 1992). Similarly, Morgan et al. (2006) have reported findings from a large UK case-control study which suggest that just over half (54%) of patients with a first episode of psychosis have an insidious onset (longer than one month). Other studies have defined the prodrome more broadly, including depressive symptoms. One early retrospective study using a sample of patients with first episode schizophrenia reported that 73% had experienced a 'prodromal' phase lasting several years, characterised by depression, negative symptoms and a decline in social functioning (Häfner et al., 1999). More recently, other authors have reported even higher estimates, suggesting that prodromal symptoms may occur in 80-90% of patients who develop psychosis, mostly 1-3 years prior to onset (McGlashan et al., 2003). These findings are partly explained by increased recognition and a broadening of what is included in the definition of the psychosis prodrome. Research

into the prodromal phase has identified a wide range of emerging psychopathology including disorganised thought, cognitive deficits, affective disturbances (particularly depression/ anxiety), self-disturbances, negative symptoms, positive symptoms and functional decline (Cornblatt et al., 2003; Gross and Huber, 1985; Häfner et al., 1999; Huber and Gross, 1989; McGlashan et al., 2003; McGorry et al., 1995; Simon et al., 2007). In medicine, the word *prodrome* refers to a period of symptoms which act as a precursor to a disease and therefore, by definition, it can only be defined retrospectively. However, McGorry and colleagues recognised that if identified prospectively this prodromal period of psychosis would provide a unique window of opportunity for early intervention, and even targeted prevention, that may lead to better long term outcomes for those affected by the disorder (McGorry et al., 2003, 1996). This represented a paradigm shift towards the identification of risk, known as the ultra high risk (UHR) approach.

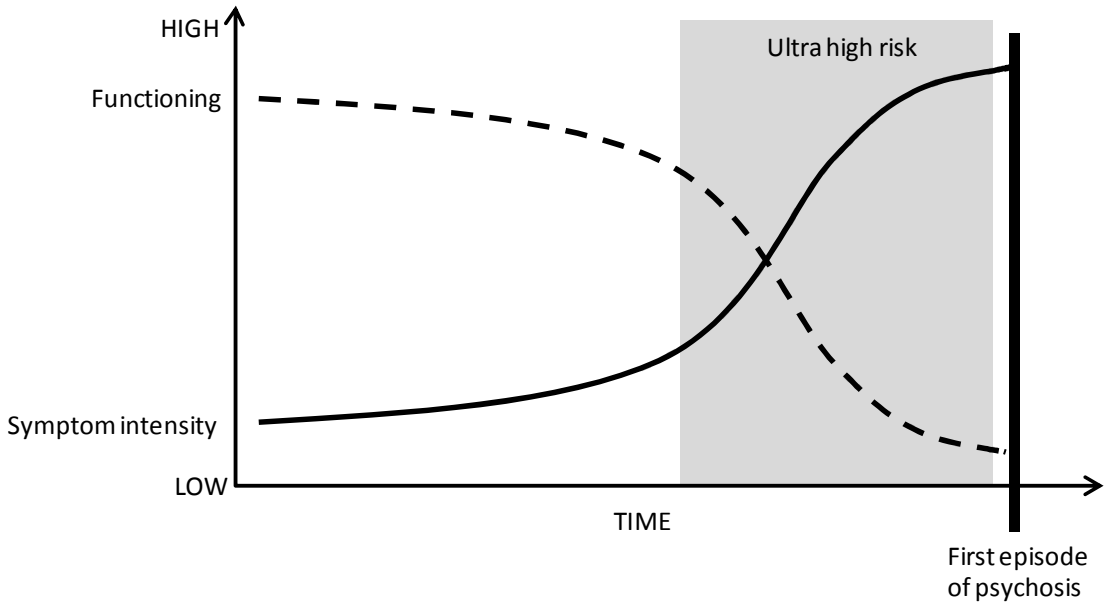


Figure 2.1 The psychosis prodrome. Adapted from (McGorry and Goldstone, 2011)

Beginning with the Personal Assessment and Crises Evaluation (PACE) clinic in Melbourne (Yung et al., 1995), research on the UHR state has been growing over the last two decades and has gathered traction worldwide, now taking place in multiple research centres and designated UHR clinical services in North America (Addington et al., 2007), Western Europe (Broome et al., 2005; Klosterkötter et al., 2005) and more recently in East Asia (e.g. Mizuno et al., 2009). While the multitude of researchers engaging in the area has led to great progress, the terminology can be confusing, with the UHR phase being variably known as the at-risk mental state (Yung et al., 1996), putative prodrome (McGlashan et al., 2003), clinical high risk syndrome (Cornblatt

et al., 2003), amongst others. This issue, along with the subtle differences between the terms, is discussed at length by Schultze-Lutter et al. (2011), and recently reviewed in a consensus paper (Fusar-Poli et al., 2013b). For the purposes of the present thesis I shall consistently refer to the UHR state.

Two approaches, one prodrome?

Almost as many assessment tools and intake criteria have been designed for the purpose of identifying the UHR state as there have been terms for it (see Fusar-Poli et al., 2013b for a recent critical review); however, these can be summarised as two approaches. The more widely used approach has been the 'close in' approach (Bell, 1992) conceived originally by McGorry, Yung and colleagues in the mid 1990s (see McGorry et al., 2003). The central concept is to use characteristics known to be present in the psychosis prodrome to prospectively identify individuals who may be most at risk of developing psychosis (shown simply in Figure 2.1). The *ultra* in UHR refers to the expectation for this transition to psychosis to occur within a relatively short space of time. Individuals are identified as being UHR on the basis of a combination of symptoms, functioning and trait and state risk factors. The PACE clinic was the first to operationalise these as:

- young age (14 to 30 years), since most psychotic illness has an onset during this time
- clinical help-seeking, since symptoms without distress are less likely to lead to the development of serious illness in the near future
- meeting criteria one of three UHR groups (see Table 2.1):
    - attenuated positive psychotic symptoms (APS)
    - brief limited intermittent psychotic symptoms (BLIPS)
    - genetic risk and decline (GRD)

    (Phillips et al., 2000; Yung et al., 2004)

The utility of the PACE criteria was supported by initial reports from the PACE clinic which showed that 41% of those meeting UHR criteria had transitioned to a first episode of psychosis within one year (Yung et al., 2003), although lower transition rates have been reported over time (Yung et al., 2007b; see below). While other criteria have been developed, the PACE criteria have remained at the core of UHR research and the most widely used alternative, the North American Criteria of Prodromal Symptoms (COPS; Miller et al., 2003), differs from the PACE criteria in details rather than in concepts (see Fusar-Poli et al., 2013b; and Schultze-Lutter et al., 2013b for critical discussion of different criteria). Specific assessment tools have been developed by each research group in order to explore these early symptoms in more detail than allowed by existing measures for psychosis patients. Consequently, UHR symptoms

are assessed against PACE criteria using the Comprehensive Assessment for the At-risk Mental State (CAARMS; Phillips et al., 2002; Yung et al., 2006b) and against the COPS using the Structured Interview for Prodromal Symptoms (SIPS; Miller et al., 2002), both of which are semi-structured interviews. Although no studies have formally compared the predictive power of the CAARMS and the SIPS in the same sample, a recent meta-analysis of transition outcomes (i.e. the proportion of UHR individuals who transition to psychosis) found no significant difference between these two instruments (Fusar-Poli et al., 2012).

Table 2.1 UHR groups defined by the PACE criteria. Adapted from Nelson et al. (2011)

Group 1: *Attenuated positive psychotic symptoms (APS)* - Presence of at least one of the following symptoms: ideas of reference, odd beliefs or magical thinking, perceptual disturbance, paranoid ideation, odd thinking and speech, odd behaviour and appearance - Frequency of symptoms: at least several times a week - Recency of symptoms: present within the last year - Duration of symptoms: present for at least 1 week and no longer than 5 years
Group 2: *Brief limited intermittent psychotic symptoms (BLIPS)* - Transient psychotic symptoms. Presence of at least one of the following: ideas of reference, magical thinking, perceptual disturbance, paranoid ideation, odd thinking or speech - Frequency of symptoms: at least several times per week - Recency of symptoms: must have occurred within the last year - Duration of episode: less than 1 week - Symptoms resolve spontaneously
Group 3: *Genetic risk and decline (GRD)* - Schizotypal personality disorder in the identified individual, or a first-degree relative with a psychotic disorder - Significant decline in mental state or functioning, maintained for at least 1 month and not longer than 5 years - This decline in functioning must have occurred within the past year

Alongside this 'close-in' approach, a growing body of literature primarily from German research groups has focused on 'basic' symptoms (e.g. Klosterkötter et al., 2001; Schultze-Lutter, 2009; Schultze-Lutter et al., 2007b), again assessed using specifically developed semi-structured interview tools such as the Bonn Scale for the Assessment of Basic Symptoms

(BSABS; see Klosterkötter et al., 1996) and more recently the Schizophrenia Proneness Instrument for Adults (SPI-A; Schultze-Lutter et al., 2007a). Based on the work of Huber since the 1960s (e.g. Gross and Huber, 1985; Huber and Gross, 1989), these are more subtle, subjective changes including disturbances of thoughts, perception, and subjective experience. In contrast to positive symptoms, basic symptoms are often only perceivable by the subject and can therefore be hard to identify clinically. However, they have been shown to be predictive of later psychotic disorder; for example, in a 10 year follow-up of clinical help-seekers referred to specialist unit for suspected psychosis, Klosterkötter et al. (2001) reported a 70% transition rate to schizophrenia among those who reported one or more basic symptoms at baseline, while a lack of basic symptoms predicted a lack of transition with 96% probability. Although the sample and time frame of this study is not widely representative, it highlights the potential importance of basic symptoms in identifying those who may develop psychosis. More recently, Schultze-Lutter et al. (2007b) defined a set of 'at risk' and 'high risk' criteria based on ten cognitive-perceptive basic symptoms (COPER) and nine cognitive disturbances (COGDIS) respectively. While there is some overlap between the two sets of criteria, they differ in terms of their predictive accuracy, with COPER showing slightly higher sensitivity (fewer false negatives) and COGDIS slightly higher specificity (fewer false positives); although both indicated a transition risk of around 20% within one year (Schultze-Lutter et al., 2007b). Basic symptoms may therefore be highly predictive of later disorder, but not within a short timescale.

In recent years the 'close in' and basic symptom paradigms have increasingly been regarded as complementary (Simon et al., 2006), and have been combined both in large scale research studies (e.g. Klosterkötter et al., 2005) and in clinical services such as Outreach and Support in South London (OASIS; Broome et al., 2005; Fusar-Poli et al., 2013c). Some have conceptualised the psychosis prodrome as a quasi-linear progression towards psychosis, with basic symptoms seen to characterise an 'early prodromal phase' and positive symptoms increasingly present in a 'late prodromal phase' (e.g. Klosterkotter et al., 2011). However, it has been noted that, while intuitively appealing, this conceptualisation is both lacking in prospective empirical support and is focused primarily on positive symptoms (Simon et al., 2007). That is, it could not account for an individual whose experiences were characterised by negative symptoms and decline in cognitive function, for example. Nonetheless, recent studies have indicated that applying both sets of high risk criteria together can improve sensitivity and individual risk estimation. Patients that meet both COPS and COGDIS criteria at baseline have been shown to have a significantly higher risk of conversion, and in a shorter time, than patients that meet only one set of criteria (Ruhrmann et al., 2010; Schultze-Lutter et al.,

2014a). This approach may therefore help to identify a more homogenous sample in terms of impairment and risk (Schultze-Lutter et al., 2014a; Simon et al., 2006). Alternatively, broadening the inclusion criteria in clinics may also help to capture individuals in need of care but who would be otherwise missed by the PACE criteria, which is heavily focused on positive symptoms (Fusar-Poli and Borgwardt, 2007).

From risk state to syndrome – moving beyond the transition to psychosis

The initial focus of the UHR research was on predicting who would transition to psychosis within a short period of time (typically 6-24months) and the evidence indicates that the UHR criteria have had significant success in this endeavour. For example the relative risk associated with UHR status compared with the general population has been reported to be as high as 400 (Cannon et al., 2008). However, the predictive validity of UHR criteria depends greatly on the sample to which they are applied (Yung and Nelson, 2011). A recent meta-analysis reported the mean risk of transition to be 18% within six months, 22% within one year, 29% within two years and 32% within three years across 27 samples (Fusar-Poli et al., 2012). However, this meta-analysis confirmed in a meta-regression that steadily lower transition risks have been reported over recent years (discussed below). Nevertheless, the majority of those who do transition to psychosis will develop a DSM-ICD schizophrenia spectrum disorder (Fusar-Poli et al., 2013a), although psychosis transition in UHR research is heavily defined on the basis of positive symptoms and may not be inclusive of all onsets of psychosis (Fusar-Poli and van Os, 2012). Indeed, in addition to positive symptoms, a range of symptomatic and neurocognitive factors have been found to predict this transition (see Fusar-Poli et al., 2013b for review), including negative symptoms (Demjaha et al., 2012; Valmaggia et al., 2013), basic symptoms (Michel et al., 2014; Ruhrmann et al., 2010), low IQ (Ziermans et al., 2014) and impaired processing speed (Carrión et al., 2013; Michel et al., 2014). Nevertheless, the fact remains that the majority of UHR individuals do not develop psychosis. Indeed, it has been suggested that the UHR state should be regarded as a 'pluripotent high risk state' (Yung et al., 2012), since it may lead to a range of outcomes other than psychosis (discussed below).

Furthermore, the rates of transition to psychosis reported in recent studies have often been lower than in early investigations. For example the mean transition rate of 22% within one year reported by Fusar-Poli et al. (2012) is around half of the 41% estimate originally reported by Yung et al. (2003). Although this has sometimes been described as a "decline" in transition rates (e.g. Yung et al., 2006c), it may be more a function of changes in the types of people recruited to study samples than a true change in risk per se (discussed in detail by Wiltink et al., 2013). UHR samples are recruited through specialised clinics in a process that

varies across studies, hence findings can be expected to vary as they are likely to reflect the type of person recruited to each sample (Fusar-Poli et al., 2014c). This will vary across sites and within the same service over time. For example, Yung et al. (2007b) showed that the duration of symptoms prior to clinical contact was less for more recent patient intakes than for earlier intakes. Put another way, subjects recruited to earlier studies are likely to have been more ill and closer to developing psychosis than those recruited to later samples. The 'decline' in transition could therefore reflect a lead-time bias, in that earlier detection may give the impression of delayed transition. While it is also possible that clinical intervention may be succeeding at preventing or delaying transition in this earlier stage, the effectiveness of UHR interventions has been debated (Amos, 2014). It has alternatively been suggested that the concentration of genuinely prodromal cases in each sample may be reducing over time as more 'false positives' (who would never have transitioned) are referred to the clinic (Yung et al., 2007b). This is potentially attributable to a greater awareness of services among referrers (Fusar-Poli et al., 2013b; Wiltink et al., 2013). Recent evidence has highlighted changes in the care pathway of UHR individuals to the PACE clinic, with referrals happening earlier and fewer contacts being made prior to specialist services, consistent with this increased awareness of UHR services (Wiltink et al., 2013).

That an individual has 'not transitioned to psychosis' does not imply that the individual is healthy. Studies into the long term outcomes of those who do not transition have indicated that many will continue to show attenuated symptoms and impaired functioning compared with the general population (Addington et al., 2011; Carrión et al., 2013; de Wit et al., 2014; Haroun et al., 2006), although some have argued that data on this has been underreported (Simon et al., 2011). While a proportion of the individuals who do not transition may show clinical remission, estimated to be around 35% by a recent meta-analysis (Simon et al., 2013), evidence relating to the exact proportion has been inconsistent (24%, Addington et al., 2011; 30%, Schlosser et al., 2012; 75%, Velthorst et al., 2011). Nonetheless, most non-converters will continue to show a mixture of other psychopathology, typically symptoms of anxiety or depression, and may transition to other nonpsychotic diagnoses (de Wit et al., 2014; Fusar-Poli et al., 2013b; Phillips et al., 2007). Moreover, the transition itself does not necessarily determine the functioning and quality of life of the individual, since someone who has transitioned may recover and experience better long term outcomes than someone whose symptoms have persisted but never met the threshold for psychosis (Yung et al., 2010a). The definition of a transition is based on an arbitrary cut-off with little consistency across measures (Fusar-Poli and van Os, 2012). Consequently, a greater emphasis has been placed on the functional outcome of UHR individuals (Wood et al., 2007) and on acknowledging the role of

UHR services as a source of support for young people currently in need of help (Yung et al., 2007b). This is also reflected in the decision of the DSM-5 task force to rename the proposed 'psychosis risk syndrome', which had sparked a great deal of discourse and debate (e.g. Carpenter, 2009; Corcoran et al., 2010; Woods et al., 2010; Yung et al., 2010b), to an 'attenuated psychosis syndrome' (Carpenter, 2011). In essence, the focus has moved from simply seeing UHR as an 'identify and prevent' risk state towards a 'diagnose and treat' syndrome, a meaningful and potentially distressing state in itself (Carpenter, 2011).

Limitations and criticisms of the UHR approach

One important limitation of the research into the UHR state is that almost all studies have been conducted using 'help-seeking' samples (see section 2.3 below for exceptions). Help-seeking is a vital part of the justification for providing clinical intervention in absence of a recognised psychiatric diagnosis; whereas patients in first episode psychosis services may be compelled to undergo a mental health assessment, this is not the case for users of UHR services, for whom help can only be received willingly. As such, clinical help-seekers may therefore represent a subgroup of individuals currently experiencing the symptoms described by the UHR criteria, while others (who may not be help-seeking) remain in the community. Although the exact proportion of UHR individuals who do not seek help is unclear (again, see section 2.3 below), the presence of this group can be hypothesised on the basis of pathways into first episode psychosis services. For example, a recent retrospective study showed that fewer than one in five psychosis patients had initiated help-seeking behaviour during the prodromal phase (O'Callaghan et al., 2010). Given that many psychosis patients experience a prodromal period that may last for several years (Häfner et al., 1999; McGlashan et al., 2003), and that not all of those presenting to first episode psychosis services within insidious onset have had prior contact with UHR services, it is likely that some prodromal individuals will remain in the community or in non-specialist services. Moreover, specialist UHR services are relatively rare, so in many communities there will be no designated service available for the treatment of psychotic symptoms prior to the onset of psychotic disorder.

Even where services are present, the referral process is by no means perfect. Delays in receiving specialist care have been estimated to be more than three years on average, with longest delays occurring internally within the health system (Fridgen et al., 2013; von Reventlow et al., 2014), meaning that even those who seek help for prodromal symptoms may be likely to transition before they reach specialist services. Furthermore, analysis of non-attenders and those who disengage from high risk services has shown similar levels of mental health difficulties and risk for psychosis (Green et al., 2011). There are also potential biases

that may be introduced through the referral process (Rietdijk et al., 2012). While a proportion of attendees refer themselves to UHR services, the majority have made prior help-seeking contacts and are referred by another agent (Fridgen et al., 2013), most commonly another health service such as a GP or general mental health team (e.g. Fusar-Poli et al., 2013c; Wiltink et al., 2013). As a consequence, the act of help-seeking from specialist UHR service may itself be a strong indicator of risk, since it usually represents the opinion of one or more referrers that the individuals is at high suspicion of developing psychosis. Therefore it is no surprise to find that the transition risk is much higher than in the general population (Fusar-Poli et al., 2012). However, despite studies acknowledging the centrality of help-seeking to the UHR state, the specific reasons for seeking help or not have been underexplored (Yung et al., 2012). Moreover, there is some indication that the distress leading to help-seeking among UHR individuals may be more attributable to nonpsychotic features such as anxiety and depression than to attenuated positive symptoms (Fusar-Poli et al., 2013b; Schultze-Lutter et al., 2013a; Wigman et al., 2012).

The UHR approach has been criticised for its near exclusive focus on positive symptoms (e.g. Simon et al., 2006). The wider acceptance of the basic symptom concept has improved things in recent years. However, in many UHR services the vast majority of patients are characterised by positive symptoms (e.g. Fusar-Poli et al., 2013c). While this could provide support for the idea that positive symptoms are central to the UHR state, it is also an artefact of the intake criteria, which not only influence which individuals are accepted to the service but also which individuals approach or are referred to the service prior to this, for example as a result of training programmes (Reynolds et al., 2014). It has therefore been argued that this UHR group may only represent a subgroup of those who might be at increased risk of developing psychosis, since other high risk individuals may instead be characterised by negative symptoms (Fusar-Poli and Borgwardt, 2007) and/or impaired social and cognitive functioning (Simon et al., 2006), which may be present throughout earlier stages of the prodrome and intensify among those who develop a disorder (e.g. McGorry and Goldstone, 2011). Moreover, there is evidence that negative symptoms increase the risk of transition to psychosis (Alderman et al., 2014; Demjaha et al., 2012; Valmaggia et al., 2013; Yung et al., 2005) and could therefore provide additional predictive value in terms of defining the UHR state. In addition, the presence of cognitive symptoms alongside psychotic symptoms appears to be more predictive of poor long term functional outcome than positive symptoms alone (Meyer et al., 2014; Michel et al., 2014; Wood et al., 2007). Yung and colleagues (2010a) have accepted that additional refinement of the UHR criteria may be needed.

Related to this, the heterogeneity of the UHR state may also present a limitation conceptually. On one hand, individuals categorised as UHR do not all share the same risk for psychosis or the same long term outcomes. As mentioned above, the presence of negative symptoms and impaired cognitive and social functioning may have an important influence in this regard. However, those who meet UHR criteria for BLIPS are also shown to be at higher risk than those who meet criteria for APS (Nelson et al., 2011). Moreover, a latent class analysis of UHR patients produced four classes, each characterised by different levels and configurations of symptoms and different levels of risk (Valmaggia et al., 2013), emphasising this heterogeneity. On the other hand, co-occurring common mental disorders, such as depression and anxiety, may be present in around three quarters of the UHR group and are associated with poor functioning (Fusar-Poli et al., 2014b). For some, this represents a blurring of the line between common mental disorder and psychosis and provides support for the idea that psychotic disorders such as schizophrenia may share a pre-psychotic prodromal stage with depression (Häfner and Maurer, 2006). Depression is recognised as a symptom dimension within psychosis (Heckers et al., 2013; van Os and Kapur, 2009). However, others have argued that since characteristic positive symptoms are often transitory or fluctuating (Simon and Umbricht, 2010), a schizophrenia perspective may be misleading; rather, UHR individuals may be better conceived as individuals who have a common mental disorder with additional psychotic features (van Os and Murray, 2013; van Os, 2014). Nonetheless, whatever the reason, the research conducted in clinical settings has shown that presenting individuals who meet the intake criteria for clinical UHR services are highly symptomatic, distressed and in need of care (Yung et al., 2013).

2.2 The psychosis continuum: an epidemiological perspective

In addition to clinical studies of individuals meeting UHR criteria, epidemiological research has established that subclinical psychotic experiences, defined narrowly as low level hallucinations and delusions, are prevalent in the general population (for reviews, see Linscott and van Os, 2013; van Os et al., 2009). In recent years these have been largely understood in relation to the proposal that these psychotic experiences exist on a phenomenological continuum with normal experience and normal expressions of personality on the one hand, and psychotic disorder on the other. This may be modelled as a “half-normal distribution” (David, 2010), as displayed in Figure 2.2, with low intensity anomalous experiences being relatively common and higher intensity psychoses occurring in far less of the population. For example, point (a) is likely to be part of normal experience, while point (c) would be considered evidence of a psychotic disorder. Point (b) may therefore represent the kinds of

experiences reported by the UHR group with attenuated positive symptoms. This framework has provided great potential for understanding variation in the severity of psychotic experiences, recognising that individuals may exist at a fixed point along the continuum (temporarily or long term) and thinking about trajectories of experiences over time, from subclinical to clinically relevant (Murphy et al., 2012). Its key message is that psychotic disorder may therefore represent a quantitative extreme of experiences present in the general population rather than one side of a qualitative dichotomy (van Os et al., 2000).

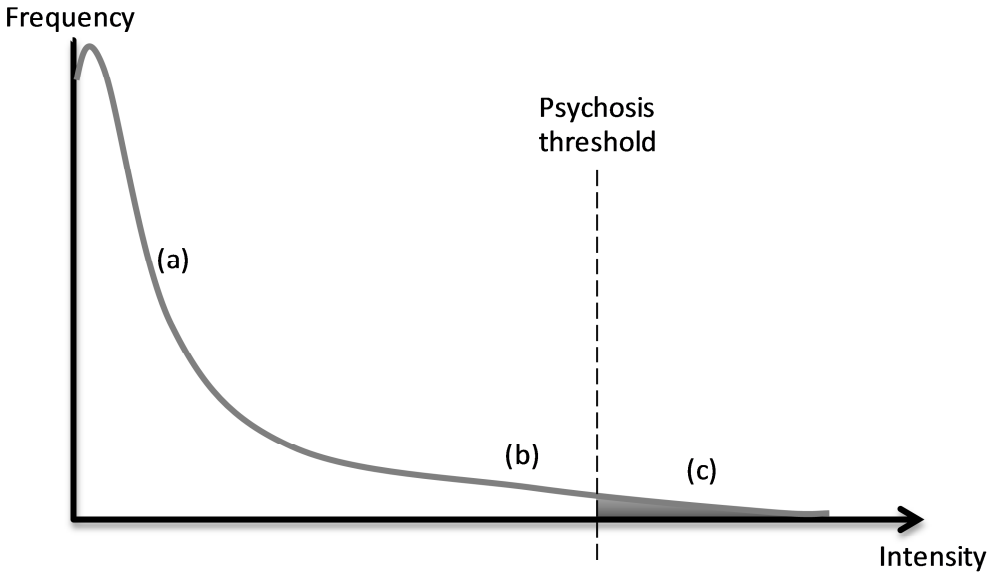


Figure 2.2 The psychosis continuum model

Moreover, Linscott and van Os (2013) have drawn attention to three separate types of continuum, which may all be important. The first is temporal continuity, which simply refers to the fact that the same psychotic experiences may persist and endure in an individual over time, and are likely to occur prior to the onset of psychotic disorder. The second is phenomenological continuity (mentioned above), which refers to the idea that psychotic symptoms lie on a continuum with normal experience in terms of how the symptoms themselves present. Low level hallucinatory experiences and frank psychotic hallucinations may be distinguished quantitatively by their intensity, but are qualitatively alike (as shown in Figure 2.2). This is supported by shared risk factors (see below) and the similar behaviour of symptoms in response to stressors, raising the possibility of a shared causal mechanism. This continuity may also exist within an individual. For example, an individual may experience some

mild paranoia at one time but one week later may experience paranoid delusions to a degree that meets UHR criteria. The phenomenological continuum model would understand this as a worsening of the same symptom rather than as two separate phenomena. Finally, the third type is structural continuity. This refers to the distribution of psychotic experiences in the population, and specifically whether individuals who do and do not go on to develop psychotic disorder belong to the same underlying population. In contrast to phenomenological continuity, structural continuity is thought to exist between individuals. For example, a second individual may experience some frequent feelings of paranoia. Although his experiences are not as severe as the first individual's, structural continuity would imply that both may confer a risk for psychotic disorder. The key question is whether experiences all lie on the same underlying construct, or whether patterns are better explained by there being multiple classes (usually two: here, related and unrelated to psychotic disorder). Linscott and van Os (2013) argue that the research on psychotic experiences in the general population supports both the models of temporal and phenomenological continua, but not necessarily the structural continuum model, since results appear consistent both with one latent class or with two. For example, using data from the second Netherlands Mental Health Survey and Incidence Study (NEMESIS II; n = 6646), van Neirop et al. (2012) have demonstrated that self-reported psychotic experiences which are not confirmed by clinical interview may be phenotypically continuous with clinically relevant psychotic symptoms but structurally discontinuous in terms of need for care. This conceptual distinction is likely to be dependent upon the wider psychopathological, developmental and psychological context of these experiences (Kaymaz and van Os, 2010). This distinction is particularly important from the UHR perspective, since the assumption of a structural continuum would imply that all individuals meeting symptomatic UHR criteria would be at similar risk for psychosis (for a given level of symptom), while structural discontinuity would account for UHR symptoms to indicate a risk for psychosis in some individuals and not in others.

Prevalence and relation to psychotic disorder

Many epidemiological studies have provided estimates of the prevalence of psychotic symptoms in the general population. The landmark systematic review by van Os et al. (2009) estimated the prevalence to be around 8%. However, a more recent update has revised this slightly to 7% (Linscott and van Os, 2013). Both of these estimates are greater than the prevalence of schizophrenia (1%) and of all psychotic disorder (3%; Perala et al., 2007), which supports the phenomenological continuum model shown in Figure 2.2 (van Os et al., 2009). However, much higher estimates for the prevalence of psychotic experiences have been

reported in individual studies, such as 17-25% in other adult samples (e.g. Morgan et al., 2009; van Os et al., 2001, 2000), higher still among children (e.g. Laurens et al., 2007; Poulton et al., 2000) and teenagers (e.g. Yung et al., 2009), and almost 99% of non-psychotic help-seekers (Yung et al., 2006a). Indeed, Linscott and van Os (2010) showed that half of the heterogeneity in rates of subclinical psychotic experiences across studies is due to study cohort and design factors. In particular, prevalence estimates derived from self-report measures, which do not allow the cross-examination of symptoms (Zammit et al., 2013), tend to be around three times higher than clinician-rated approaches (direct comparison, Horwood et al., 2008; review, Linscott and van Os, 2013). However, Linscott and van Os (2013) have argued that higher prevalence rates do not necessarily make self-report measures less valid and, moreover, observer interviews may also be affected by bias (Linscott and van Os, 2010). Furthermore, several studies have indicated that self-reported subclinical psychotic experiences may still confer an increased risk for psychotic disorder (see Kaymaz et al., 2012 for a review) even when they are deemed to be 'false-positives' by subsequent clinical interview (Bak et al., 2003a). Similar findings have led van Nierop and colleagues to describe such experiences as the softest expression of an extended psychosis phenotype (van Nierop et al., 2012).

The validity of this extended phenotype as a whole has been well demonstrated. Psychotic experiences have been shown to be associated with many of the same risk factors as psychotic disorder, including higher prevalence with younger age, minority or migrant status, lower income, less education, unmarried status and unemployment, and with exposure to urbanicity, traumatic life events, recreational drugs including alcohol and cannabis, and a family history of mental disorder (again, see Linscott and van Os, 2013; van Os et al., 2009). Perhaps more pertinently, from a UHR perspective, the model has also shown some predictive validity: several longitudinal studies have demonstrated that individuals reporting psychotic experiences are at increased risk of developing later psychotic disorder. This is vital for providing a population reference point against which the transition risk conferred by meeting UHR criteria can be judged (Kaymaz et al., 2012). In one major example, Hanssen et al. (2005) reported a 2-year transition rate of 8% for those who endorsed one or more incident psychotic experience in the preceding 12 months (65 times more than those who reported no psychotic experiences, although the confidence intervals around this estimate were very wide). This rose to around 15% for those who were also experiencing depression and 21% for those who endorsed multiple incident psychotic experiences. The initial figure is similar to the 7% transition risk tentatively reported in a recent meta-analysis of community psychotic experiences (Linscott and van Os, 2013), while the latter figures are comparable with the many estimates from the UHR literature (e.g. Ruhrmann et al., 2010; Simon and Umbricht, 2010;

Yung et al., 2008). Similarly, Poulton et al.'s (2000) 15-year follow up reports that of those endorsing "strong psychotic-type symptoms" at age 11, 25% had developed a schizophreniform disorder at age 26, 70% had schizophrenic symptoms, and 90% had some social or occupational impairment. Nevertheless, in an important meta-analysis (which included these two studies) the yearly transition risk associated with self-reported psychotic experiences in the general population was found to be much lower: 0.6% among those who reported psychotic experiences and 0.2% among those who did not (Kaymaz et al., 2012). Although psychotic experiences may still provide a valid population for studying the aetiology of psychosis (Kelleher and Cannon, 2011), the difference in predictive power between psychotic experiences in the general population and the UHR criteria in clinical populations highlights the central point that, whether the difference is quantitative or qualitative, some psychotic experiences are associated with serious clinical problems, while others are not.

Distinguishing the benign from the problematic

In general, it seems that the greater the frequency and severity of the psychotic experiences the greater the likelihood of long term clinical problems (Kaymaz et al., 2012). Some authors have drawn a meaningful distinction between clinically relevant "psychotic symptoms" (prevalence around 4%), which are associated with features such as distress and help-seeking but do not reach the threshold for psychotic disorder, and "true" subclinical psychotic experiences (van Os et al., 2009). Along with an increased risk for future psychotic disorder, these elements reflect the same conception of what is 'problematic' as the UHR approach. Indeed, help-seeking is perhaps the most obvious distinction between those with psychotic experiences in the general population and those who present at UHR services, and is at the centre of the distinction between what is 'normal' and what is clinically relevant, both in mental health in general (Spitzer, 1973) and specifically for early psychosis (Carpenter, 2009). However, there has been surprisingly little research into the factors that influence the development of help-seeking behaviour and a need for care, for a given level of symptoms (Kaymaz and van Os, 2010).

One recent study used data from the UK Adult Psychiatric Morbidity Survey to demonstrate that self-reported subclinical experiences of thought-control, paranoia or strange experiences doubled the odds of attending a GP for emotional problems compared to individuals with no psychotic symptoms, while paranoia was linked to an almost threefold increase in receiving counselling or therapy and multiple psychotic experiences were to have a cumulative effect with regard to increasing chances of help-seeking behaviour (Murphy et al., 2012). Nevertheless, other findings have suggested that psychotic experiences may not

significantly contribute to the likelihood of help-seeking from professional health services once depressive symptoms are taken into account (Kobayashi et al., 2011). Associations have been found between need for care and the severity and frequency of psychotic symptoms in the general population (Bak et al., 2003b; Murphy et al., 2012), while help-seeking behaviour has also been found to be associated with comorbidity (Green et al., 2011; Rietdijk et al., 2011) and symptom content; for example auditory hallucinations (Daalman et al., 2011; Stip and Letourneau, 2009). Nevertheless, these features do not always lead to help-seeking. For example, in the Avon Longitudinal Study of Parent and Children (ALSPAC; Golding et al., 2001), a representative general population cohort study of adolescents from South West England, Zammit et al. (2013) found that even among those whose psychotic experiences met criteria for a psychotic disorder, half did not seek any clinical help, despite reporting distress. Other factors may also influence help-seeking, such as age, gender and education (e.g. Murphy et al., 2012), ethnicity and cultural expectations (Maginn et al., 2004; Morgan et al., 2005), attitude towards health services and mental health (Yap et al., 2013), and presence of adequate support outside of clinical services; for example through family or religious institutions (Maulik et al., 2009; Shaw et al., 1999).

Several studies have shown that the majority (approximately 80%) of psychotic experiences reported in community samples are transient (Linscott and van Os, 2013) and may not be problematic in isolation. However, the proneness-persistence-impairment model suggests that exposure to environmental stress (such as trauma) may cause psychotic experiences to persist (van Os et al., 2009), making them more likely to be associated with distress and impairment in the present and a greater risk for future psychotic disorder (van Os et al., 2010, 2009). Nevertheless, several authors have expressed concerns about the measurement of persistence. For example, longitudinal studies which measure the presence of a symptom at two time points fail to distinguish between potential courses of that symptom between time points; that is, whether it is continuously present, frequently recurring, or in remission for the majority of the period (Linscott and van Os, 2013). Studies which measure psychotic experiences at multiple time-points are likely to be better able to determine the relevance of the trajectory of symptoms, as has been done using the ALSPAC cohort (Thapar et al., 2012). However, this study was underpowered to differentiate between trajectory groups. Experience sampling methods could potentially elucidate this area but such data have not yet been reported. Therefore conclusions can only be tentatively drawn. In a meta-analysis of psychotic experiences in children and adolescents, Kelleher et al. (2012a) have noted that although psychotic experiences are more common in children, they become increasingly

abnormal and associated with psychopathology through mid-adolescence. However, it is not clear whether this is a result of persistence or of later onset being more problematic.

Nevertheless, the frequency, intensity and persistence of psychotic experiences may not be enough to define them as problematic; cognitive appraisals have also been put forward as another important distinguishing factor, particularly if experiences are seen as externally generated, personally significant, and uncontrollable (Garety et al., 2001; Morrison, 2001). Studies comparing individuals experiencing persistent psychotic phenomena with and without a need for care (i.e. distress and clinical help-seeking) have provided support for this. Patients with psychosis may be more likely to attribute their experiences to an external agent, to see them as more personally significant and find them more distressing, while non-need for care individuals (with comparable experiences) may be more likely to see them as part of the normal range of human experience and show lower levels of distress (Brett et al., 2007; Lovatt et al., 2010). In addition, evidence has indicated that auditory verbal hallucinations are more likely to lead to a need for care if they are negative or unpleasant in content, have a negative impact on functioning, have little relation to contextual life-events such as mourning, have onset in early adulthood, and if the individual perceived the voices to have high power and themselves to have low control over their symptoms (see Johns et al., 2014 for review). Indeed it has been reported that the content of auditory hallucinations is more predictive of a need for care than their frequency or intensity (Daalman et al., 2011; Stip and Letourneau, 2009). Individuals without a need for care also report less maladaptive coping (Bak et al., 2003b) and score lower on maladaptive response styles in experimental conditions (Ward et al., 2014). Lovatt et al. (2010) also showed that while the experience of trauma predicts the presence of psychotic experiences it does not predict need for care. However, interpersonal trauma was specifically associated with more malign personalising appraisals of these experiences. These findings suggest that cognitive appraisals may play a key role in this distinction and may potentially mediate the association between certain risk factors and psychosis (Lovatt et al., 2010). They may also provide a mechanism by which depression increases the problematic nature of psychotic experiences (Krabbendam et al., 2005; Yung et al., 2007a), consequently antidepressants may improve psychotic symptoms by reducing the impact of maladaptive appraisals (Fusar-Poli et al., 2007).

Much like the pattern described in UHR populations, there is a strong overlap between subclinical psychotic experiences and common mental disorders. Psychotic experiences are common among individuals with depression (Wigman et al., 2011; Yung et al., 2006a) and anxious/depressive psychopathology is common among those reporting psychotic experiences in the general population (Kelleher et al., 2012b; Verdoux et al., 1999; Wigman et al., 2012),

even among so called false positives (van Nierop et al., 2012). Moreover, this association may be specific to certain types of psychotic experiences, such as bizarre experiences and persecutory ideation (Armando et al., 2010). Wigman and colleagues have used structural equation modelling to tease out the nature of this relationship, finding that although depression and psychotic experiences tended to co-occur, neither predicted the other longitudinally (Wigman et al., 2011). It is thus possible that both kinds of experience may share a common aetiology, such as a reaction to psychosocial stress. There is also tentative evidence for a shared genetic component in findings that both subclinical psychotic experiences and psychotic disorder are more associated with a family history of general psychiatric problems than of psychosis (Mortensen et al., 2010; Zammit et al., 2008). Alternatively, psychotic experiences in the context of common mental disorder may be seen as an index of severity (Kelleher et al., 2014). For example, adolescents who are depressed with additional psychotic experiences have a greatly elevated risk of suicidal behaviours compared with those who do not have psychotic experiences (Kelleher et al., 2014, 2013). The combination of psychotic features with anxiety and depression may contribute to the development of distress and need for care, mediated by accumulating comorbidities and culminating in the specific help-seeking behaviour that distinguishes the UHR state from community psychotic experiences (Fusar-Poli et al., 2014b).

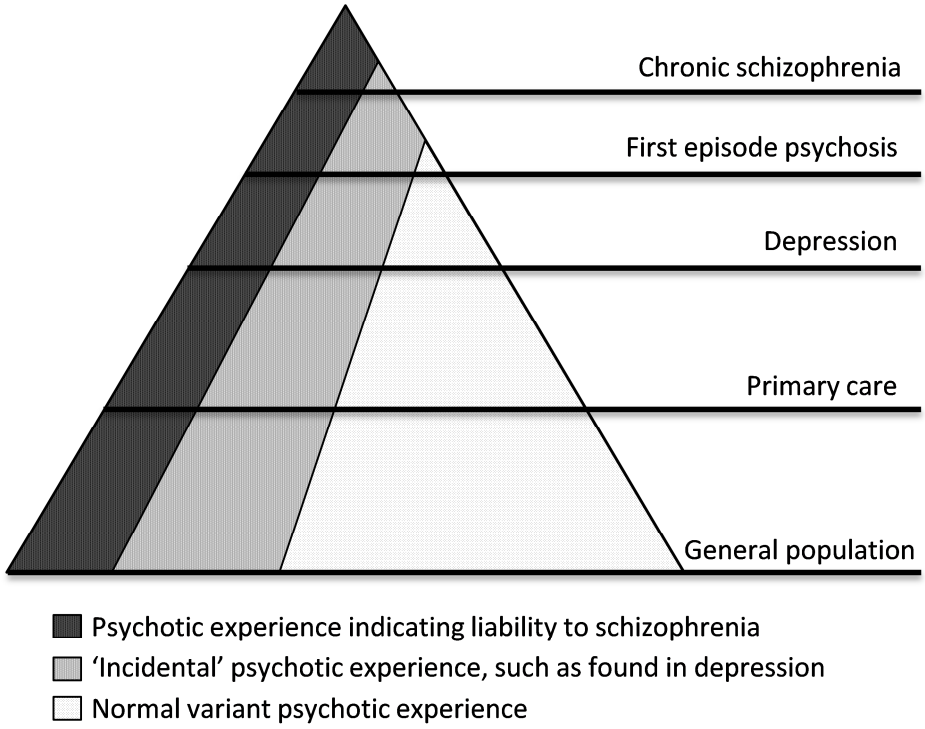


Figure 2.3 Hypothesized proportion of each type of psychotic experience in different populations. (Reproduced from Fusar-Poli et al., 2014b)

Yung and colleagues (Nelson and Yung, 2009; Yung et al., 2009) have suggested a model which defines three types of psychotic experience: the first is a natural and normal expression of personality, and is benign in terms of mental health. The second type represents an "incidental" or secondary psychotic experience that is related to some other (nonpsychotic) psychopathology, such as depression, and is supported by studies which show psychotic symptoms decreasing in parallel as depression and anxiety symptoms are treated (Addington et al., 2011; Yung et al., 2007a). Finally, the third type is a "core" psychotic experience, which marks the emergence of an underlying psychotic disorder. The authors explain that while the third type of psychotic experience may be regarded as representing a clinical risk for psychosis, psychotic experiences that are incidental to common mental disorders would not be expected to confer this risk but may still impact on an individual's present functioning and need for care (Fusar-Poli et al., 2014b). In this model all three types of psychotic experience may be present across populations, but will appear in different proportions in different subsets of the population (see Figure 2.3). Consequently, in unselected general population samples one would expect the majority of psychotic experiences identified to be of the benign variety, with very few reflecting the emergence of psychotic disorder, whereas in clinical samples a greater proportion of psychotic experiences found would be of clinical concern. This difference could explain the lower risk conferred by psychotic experiences in the general population compared with those in UHR clinics, as well the greater impact of psychotic experiences when found in combination with common mental disorder. It also follows that cross-sectional studies may be able to distinguish incidental and core psychotic experiences from the benign variety on the basis of current distress and help-seeking behaviour, whereas longitudinal follow-up would be required to distinguish the core from the incidental. Nevertheless, as the focus of UHR care shifted from risk to syndrome this represents the recognition that both types of experience would be clinically important.

Limitations and relation to the UHR state

One important limitation of the research into psychotic experiences in the general population has been the lack of consistency in defining what is to be included as a psychotic experience. In the phenomenological continuum model presented in Figure 2.2 it is clear that the line could be drawn at any point along the continuum, and indeed studies have used a great range of different assessment tools and definitions that are likely to have done just this. Temporally, prevalence estimates derived from a tool that assesses lifetime experiences may be higher and more susceptible to recall bias than tools which encompass shorter timeframes.

From a phenomenological perspective, the prevalence of psychotic experiences is likely to be greater on a tool that measures less severe experiences compared with a diagnostic tool for psychosis or an UHR clinical assessment. Likewise, the estimated prevalence of 'one or more psychotic experience' is likely to be greater when using a tool that covers a wider range of experiences in a larger number of items, while a tool that examines only a few symptoms is likely to lead to underestimates (van Os et al., 2009). For example, using the Community Assessment of Psychotic Experiences (Stefanis et al., 2002), which is a 42-item questionnaire of lifetime psychotic experiences, studies have reported the prevalence of endorsing one or more positive item to be as high as 98% in the general population (Armando et al., 2012). Experiences that are so frequent cannot be considered to be psychotic in any meaningful sense of the word; however, the phenomenological continuum would predict that they would still behave in a similar way to psychotic symptoms. Accordingly, Armando and colleagues found that frequent persecutory ideas (present in over 60% of the sample) were associated with distress, functional impairment, depression, anxiety and help-seeking.

These findings are important for understanding the aetiology of psychosis and for appreciating the nonspecific natures of psychotic experiences. Nevertheless they are limited in how straightforwardly they can be applied to the UHR state. Firstly, several authors have made the point that samples used in UHR research are not epidemiological but rather are highly selected and 'enriched' by distress and specific help-seeking (Fusar-Poli et al., 2014a; Kaymaz et al., 2012; Yung et al., 2010b). While some community individuals with psychotic experiences may be distressed and may seek help, they will not have gone through the same enrichment-by-referral process that I described in section 2.1 above and are unlikely to have the same high rates of comorbid common mental disorder (van Os and Linscott, 2012). Furthermore, the selection process for samples varies widely across clinical UHR services, so each UHR sample can be regarded to some extent as opportunistic (Fusar-Poli et al., 2014c). On the other hand, while many of the general population samples used are highly representative, the non-need for care participants studied by Brett, Peters and colleagues (e.g. Brett et al., 2014, 2007; Lovatt et al., 2010) were also highly selected and unrepresentative of the general population.

A second difference relates to symptoms. Schultze-Lutter and colleagues (2011) have argued that many studies of psychotic experiences cannot be seen to represent UHR individuals because they are characterised by uncertainty over the validity of the experiences they measure, as a result of using self-report questionnaires or structured interviews (Hanssen et al., 2003). They have also demonstrated that self-reported experiences are a poor estimate of clinician-rated psychotic symptoms (Schultze-Lutter et al., 2014b), which would cover all symptoms assessed in UHR studies. The overlap with depression and low mood in community

samples may further decrease the validity of self-reported psychotic experiences as a result of biases (Seemüller et al., 2012). Furthermore, UHR criteria correspond to a cluster of symptoms and impairments of defined severity and frequency, as opposed to single phenomena. The criteria have been developed and validated in help-seeking subjects, and the assessment instruments are conducted by trained experts in clinical settings; they are somewhat incomparable with those used in community research (Fusar-Poli et al., 2014a; Kaymaz et al., 2012). It is therefore likely that UHR criteria would be less prevalent than isolated psychotic experiences or symptoms. However, their exact prevalence in the general population cannot be inferred from epidemiological studies of psychotic experiences (Schultze-Lutter et al., 2014b).

2.3 Applying the UHR criteria to the general population

There is good evidence that individuals in an UHR state are symptomatic, distressed and help-seeking. Nevertheless, the evidence informing our understanding of this UHR state is largely based on studies of people who presented to specialised mental health services seeking clinical help and is therefore partly circular (Schultze-Lutter et al., 2013b). Similarly the fact that the majority of the individuals in UHR clinics present with attenuated positive symptoms may simply be an artefact of the positive-symptom-centric inclusion criteria used by the majority of UHR services. It remains unclear whether there is another population that is experiencing similar symptoms, or experiencing a similar need for care and/or increased risk for psychosis, but is not seen by mental health services, or indeed what the relative size and natural history of this non-clinical group might be. Yet the prevalence of UHR criteria in the general population has potentially important implications for their validity, and for the relative importance of the different symptoms with regard to conferring an increased risk for psychosis or a need for care. Schimmelmann et al. (2013) have outlined these implications nicely in the context of children and adolescents, but the arguments apply to all populations (see Figure 2.4). Namely, if the UHR criteria are shown to be common in the general population then they are probably a poor way of discriminating between those genuinely at risk and those who are not, and thus should perhaps be revised. In contrast, if symptoms meeting UHR criteria are rare in the general population and are either predictive of psychosis, or are markers of distress and poor functioning in themselves, then this would represent an unmet need which services should look to address.

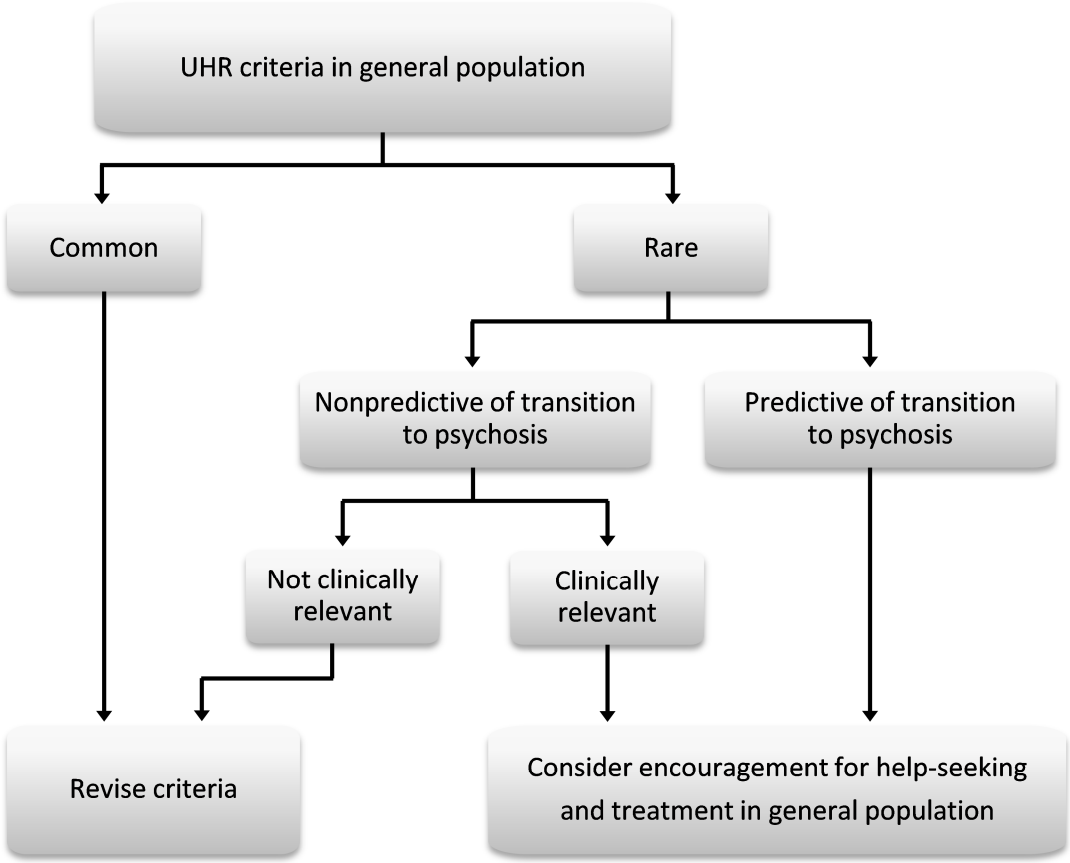


Figure 2.4 Epidemiology of UHR criteria: potential implications. (Adapted from Schimmelmann et al., 2013)

Despite many studies highlighting the importance of determining the prevalence and meaning of the UHR state in the general population, to date, very few studies have attempted to do this. Some have examined UHR symptoms in a control group as part of assessing the reliability of assessment tools (e.g. Klosterkotter et al., 1997; Yung et al., 2005), but to my knowledge only five studies have reported prevalence estimates based on representative samples from the general population. Schimmelmann et al. (2011) were the first to provide an answer to the question of what proportion of the general population would meet current UHR criteria, conducting telephone interviews using the SIPS with a random sample of 58 individuals aged 16-35 from Canton Bern, Switzerland. Of these, only one individual met UHR criteria according to the COPS, equating to a three-month prevalence of 2%. However, the authors neatly also applied other UHR criteria to demonstrate differences in the number of individuals identified, with revised estimates of 10% (n = 6) for the 2002 version of the PACE criteria (e.g. Phillips et al., 2002) but no individuals meeting either the more recent PACE criteria (Yung et al., 2006b), which includes an obligate functional impairment, or the COPER or COGDIS criteria for basic symptoms. This again highlights the issues of incomparability between different sets of criteria (as in Schultze-Lutter et al., 2013b) and more practically highlights the importance of deciding exactly which criteria to use, since this decision can

impact heavily on the results. Likewise, the authors note that the prevalence of sub-threshold UHR symptoms was much higher (21%; n = 12); specifically, 12% (n = 7) for sub-threshold attenuated positive symptoms (akin to psychotic experiences described above) and 16% (n = 9) for basic symptoms (reported with insufficient frequency to meet COPER or COGDIS criteria). Yet, the presence of these sub-threshold symptoms was shown to be associated with lower psychosocial functioning and co-morbid Axis I diagnoses, providing support for the phenomenological continuum. This also highlights the importance of the role played by the cut-off point in these assessments and that changing this could drastically change results, particularly strikingly in a small sample. This study therefore represented an important first step in terms of defining the prevalence; however, this should be regarded more as a feasibility study since the sample size is too small to draw reliable conclusions. These findings therefore need replication in a larger sample.

Some support is provided by two studies of UHR symptoms in adolescents. Firstly, Zammit et al. (2013) also found a low prevalence of UHR status compared with previous reports of psychotic experiences. Face to face interviews were conducted with 4700 older adolescents (aged 18) from the ALSPAC sample, of whom 35 individuals met UHR criteria (again defined using the COPS), a prevalence of 0.7%. Of these, 20 individuals met criteria for APS (0.4%) and 20 for BLIPS (0.4%), with five individuals experiencing both. Nevertheless, UHR symptoms were not assessed directly using the SIPS, but rather the data were derived from another assessment which the authors acknowledge is not wholly comparable. As such this limits the validity of the estimate and its comparability with other studies. Nonetheless, this study presented the additional finding that only one UHR individual (5%) had sought help for their experiences, which raises the possibility that there may be an unmet need in this group. Secondly, a general population cross-sectional study in Ireland (Kelleher et al., 2012d) investigated the prevalence of the UHR state among a random sample of 212 young adolescents (aged 11-13). Again using the COPS, the prevalence of UHR was estimated to be 8.1% (n = 19); specifically, 7.7% met APS criteria and 3.5% met criteria for BLIPS (again there was some overlap). Like Schimmelmann et al., Kelleher et al. applied the PACE criteria with and without the functional impairment criterion, estimating the prevalence to be 7.7% and 0.9% respectively, although the number and breakdown of these individuals is not reported. Importantly, the authors also report that 89% of those who met APS criteria reported being distressed by their symptoms and that UHR status was again associated with poorer psychosocial functioning and a significantly greater likelihood of a past or present Axis I diagnosis, particularly affective disorders. An important strength of this study is that data were collected through face to face interviews, which provide a more accurate recreation of the

clinical assessment process used in UHR services. Like Zammit et al., Kelleher et al. also acknowledge that they did not explore UHR symptoms directly using the SIPS. However, they did modify their interview with specific SIPS items in order to assess symptoms against the COPS and PACE criteria, which is an improvement on assessing criteria post-hoc against the information available. Nevertheless, the estimates are limited to some extent by the use of such a young sample. Although the SIPS and the CAARMS do not specify lower age limits, the validity of applying them to child samples has been questioned (see Schimmelmann et al., 2013 for review). This matter has not been settled, but certainly the sample is over a decade younger than those typically presenting to UHR services in the UK (mean 23 years; Fusar-Poli et al., 2013c), which raises questions about how useful findings are for informing services.

In the last year, data have also been published from the Bern Epidemiological At-Risk Study (BEAR), again from Canton Bern in Switzerland (Schultze-Lutter et al., 2013a). This large random sample from the general population included 1229 individuals aged 16-40 years (mean 30 years), which is close to the intake criteria for UHR services and was broadly representative of the study population. Using the SIPS to assess UHR symptoms against the criteria for an Attenuated Psychosis Syndrome (included in Section 3 of DSM-5), Schultze-Lutter et al. (2013a) report an initial prevalence of 12.9% for UHR symptoms reaching the required severity threshold. However, over half of these were reported with no accompanying distress. Moreover, the Attenuated Psychosis Syndrome also incorporates frequency (symptoms experienced weekly for the last month), onset/worsening (symptoms onset or worsen in the last year) and distress/disability (distressing and impacting on behaviour) criteria (American Psychiatric Association, 2013). The authors demonstrate that inclusion of these additional criteria drastically reduced this estimate: only 3.8% met the frequency criterion, 1.1% met the onset/worsening criterion and 7.0% met the distress/disability criterion. Together only four individuals (0.3%) met all criteria, leading the authors to suggest revising and extending the onset/worsening criterion, which was responsible for excluding 28 of the 32 individuals who reported feeling distressed or disabled by their UHR symptoms and might therefore represent those who would benefit from intervention. Under these revised criteria the authors report a prevalence of 2.6%. The main strength of the BEAR study is its age-appropriate and relatively large epidemiological sample, which was achieved by the decision to use telephone interviews to efficiently interview a large number of people across a wide area. Importantly, the authors also explored help-seeking behaviour and revealed that although psychotic symptoms were associated with greater help-seeking, no participants spontaneously identified these symptoms as the reason for them seeking help when asked an open question. Instead this tended to be attributed to depression, anxiety or relationship problems with a partner. This

finding is helpful for understanding potential differences between patients in UHR services and those meeting UHR criteria in the general population.

One study to date has examined the prevalence of basic symptoms in the general population (Meng et al., 2009). The presence of basic symptoms was assessed using the BSABS in a random sample of 99 adolescents aged 14-20 (mean 16 years) from the general population of Basel, Switzerland. The main finding was that one or more basic symptoms was present in 30% of the general population sample, compared with 81% of a nonpsychotic psychiatric sample and 97% of an early onset psychosis sample. Despite showing good discriminant validity between the groups, particularly for certain cognitive symptoms, the authors comment that the variation in prevalence of individual single basic symptoms is too great to use them in general population screening. However, they do recommend that including a set of specific basic symptoms might add value to existing UHR approaches, describing something very like the COGDIS criteria (Schultze-Lutter et al., 2007b). Although Meng et al. did not report any prevalence estimates for UHR criteria, these data were reanalysed by Schultze-Lutter et al. (2012), which suggested that 3.1% of general population would have met COGDIS criteria and 8.0% would have met COPER criteria. However, these estimates were derived from the BSABS rather than assessed directly using the SPI-A, for which the criteria were defined. The authors have suggested that since the BSABS does not measure the frequency or duration of symptoms, frequency requirements of COPER and COGDIS could not be taken into account, and thus the figures reported may be an overestimate of the prevalence of UHR basic symptoms in young people.

Synthesis and limitations of current research

Taken together, these findings provide reasonable evidence that a minority of individuals in the general population experience symptoms that are sufficient for meeting UHR criteria. They also indicate that these symptoms may be associated with distress and comorbidity of Axis I disorders as seen in UHR clinical services (Fusar-Poli et al., 2014b). It is also clear that more individuals meet symptomatic UHR criteria than also experience a concurrent decline in functioning, which makes sense given that individuals sampled at random in the community are not pre-selected based on their functioning as they (implicitly) are in clinical populations. However, in determining the exact prevalence the picture is not a consistent one. Each of these five studies reports a different prevalence for individuals who meet UHR criteria, ranging from 0.7% to 12.9% depending on what criteria are applied. The samples themselves were very different, both in terms of age (e.g. 11-13 years versus mean 30 years) and nationality. However, the comparability of these estimates is also reduced by the use of different

assessment tools across the studies, and limited further by the application of UHR criteria to data collected from assessment tools other than those designed for the task. For example, two studies provide prevalence estimates based on PACE UHR criteria but neither study assessed UHR symptoms using the CAARMS. Comparison of COPS and PACE criteria within the same sample were also inconsistent, with PACE criteria (sans functional impairment) giving a higher estimate in Schimmelman et al.'s study but a slightly lower estimate in the study by Kelleher et al. This is likely to be in part due to the COPS' more recent onset criterion. However, the exact overlap of subjects identified by different criteria is not reported.

Nevertheless, even just comparing the three studies which assessed UHR status based on the SIPS, prevalence estimates still vary from 0.7% to 8.1%. To some extent this may reflect differences between populations, since psychotic experiences have been shown to occur at greater rates among children than among adults (e.g. Laurens et al., 2007; Poulton et al., 2000) it may be unsurprising to find that the prevalence of UHR was highest in the study of 11-13 year olds (Kelleher et al., 2012d). Nevertheless there may also be other factors affecting these differences. For example the ALSPAC data represents a sample who have been followed up at various points since birth (Zammit et al., 2013), it is therefore possible that attrition may have disproportionately affected individuals who were also exposed to a higher level of risk factors such as childhood trauma and drug use. In an earlier study, Zammit et al. (2008) reported that non-attendees were more likely to be of lower socioeconomic status, lower education, male and belonging to an ethnic minority, all of which are risk factors for psychosis. Equally, the ALSPAC sample is not ethnically diverse, with over 96% of participants being White (Boyd et al., 2013). The low prevalence of UHR criteria in this sample may therefore be partly a result of selecting less susceptible individuals. Three of the five studies involved samples from Switzerland, taking advantage of its obligatory population register, which provides a very large and inclusive sampling pool akin to the total population (Schultze-Lutter et al., 2013a). However, none of these studies report information about ethnicity (Meng et al., 2009; Schimmelmann et al., 2011; Schultze-Lutter et al., 2013a). It is therefore not clear how well these findings would translate to other populations, particularly those with high proportions of ethnic minorities. Similarly, the prevalence of basic symptoms has not been examined in a non-German speaking sample, so again it is unclear how well this would translate to other populations.

In terms of providing a comparison for current UHR services, in particular OASIS in London, the utility of these studies is mixed. As mentioned above, the mean age of Kelleher et al.'s sample is much younger than that of those seen by OASIS (mean 23 years) and is therefore the least comparable. The two studies from Canton Bern are much more closely matched in terms

of age range (16-35 years, Schimmelmann et al., 2011; 16-40 years, Schultze-Lutter et al., 2013a), although the mean age in the BEAR study (30 years) is older than the average OASIS client. In contrast, Kelleher et al.'s study, along with the ALSPAC cohort, has the methodological advantage of having been conducted using face to face interviews, while the use of telephone interviews is perhaps the biggest potential weakness in the Bern studies, since this diverges from the normal experience of a clinical interview and from the context for which the tools were designed. Schultze-Lutter and colleagues have previously reported excellent concordance rates when comparing telephone and face to face methods (86-100%; Michel et al., 2012) and provided a high level of training to interviewers in the BEAR study (Schultze-Lutter et al., 2013a). However, the authors note that the use of telephone contacts also created a slight selection bias, over representing the 36-40 age bracket and underrepresenting those aged 26-30, although the findings did not indicate an effect of age.

Finally, all five studies are limited in their conclusions by the fact that their measurement of UHR symptoms was cross-sectional. The underlying assumption of assessing UHR symptoms in the general population (i.e. that individuals meeting these criteria are at high risk of developing psychosis) cannot be tested without a longitudinal follow-up. Given Yung et al.'s (2008) statement that the population from which UHR subjects are drawn affects the predictive validity of the criteria, and given the substantial difference between the sub-1% yearly transition risk associated with self-reported psychotic experiences in the community (Kaymaz et al., 2012) and the 22% yearly transition risk in UHR populations (Fusar-Poli et al., 2012), the current evidence cannot tell us for sure what level of risk (if any) might be associated with UHR criteria in the community. While there is good evidence to suggest that community UHR symptoms might well create a current need for care, being associated with distress, comorbidity and to some extent help-seeking, this information is not reported in relation to basic symptoms. As a result, this area certainly warrants further study.

Conclusion

Research into the UHR state has increased exponentially over the last two decades. Nevertheless, despite a number of studies attempting to define the prevalence of UHR criteria in the general population, findings have been variably limited by insufficient sample size, variations in sample age, and unrepresentative assessment methods compared with clinical practice. To date, no study has examined the prevalence of the UHR state in the same population as served by a clinical UHR service and using the same assessment procedure. Likewise, no study has explored the differences between UHR individuals in the population and patients currently presenting to UHR services. In addition, recent findings have indicated that

previous work may have relied too heavily on positive symptoms alone and that the role of additional basic symptoms, negative symptoms and common mental disorder in determining need for care and help-seeking behaviour may warrant particular attention. Knowing this information may have important implications for the appropriateness of the UHR criteria currently in use and for the level of outreach that UHR services are engaged in.

2.4 Aims of the present thesis

1) Define the prevalence of subjects meeting UHR criteria in the general population
2) Establish what proportion of community subjects who meet UHR criteria are distressed, help-seeking or have a need for care
3) Compare community UHR subjects to those currently seeking help from a specialist UHR service

II. PILOT WORK

CHAPTER 3 PSYCHOTIC EXPERIENCES, HELP-SEEKING AND SUICIDALITY IN THE GENERAL POPULATION: THE IMPORTANCE OF COMMON MENTAL DISORDER

In this chapter I outline the pilot work for this thesis, which was undertaken using secondary data from the South East London Community Health study (SELCoH; Hatch et al., 2011), a general health survey conducted in the London boroughs of Southwark and Lambeth. This is the same catchment area served by the local ultra high risk for psychosis (UHR) service, Outreach and Support in South London (OASIS; Broome et al., 2005; Fusar-Poli et al., 2013c). Therefore, SELCoH data provided an ideal opportunity to establish the baseline rate of psychotic experiences within the target population and to explore some of the themes described in the previous chapter. The results and conclusions of these analyses helped to develop and refine the hypotheses for the thesis.

3.1 Background and Aims

Epidemiological research has revealed that occasional (positive) psychotic experiences are far more common in the general population than psychotic disorders (prevalence around 7%; Linscott and van Os, 2013; van Os et al., 2009). Although the use of different measures, along with cohort and design features, has contributed to very different prevalence estimates being reported across studies, these subclinical psychotic experiences have been characterised as an extended phenotype lying on a phenomenological continuum from clinical symptoms of psychotic disorder, through psychotic symptoms in nonpsychotic disorder, to subclinical psychotic experiences in otherwise healthy individuals (Fusar-Poli et al., 2014b; van Os and Linscott, 2012; van Os et al., 2009). Supporting this model, psychotic experiences in the community have been shown to be associated with many of the same risk factors as psychotic disorder, including younger age, ethnic minority and migrant status, lower pay, less education, being unemployed, being unmarried, exposure to cannabis and other substances, exposure to trauma and stress, urbanicity and a family history of mental illness (see Linscott and van Os, 2013). There is some evidence that subclinical psychotic experiences are associated with a modest increased risk for psychotic disorder (see Kaymaz et al., 2012 for review). However, the absolute significance of this has been debated (Fusar-Poli et al., 2014c). Moreover, the majority of psychotic experiences are transient and are not associated with any clinical impairment (van Os et al., 2009), and may not even be distressing (e.g. Brett et al., 2014).

Nevertheless, it is well established that psychotic experiences in the present show a great deal of overlap with common mental disorders such as depression and anxiety, in both clinical and community samples, leading to more distress, poorer coping, and lower treatment efficacy (Kelleher et al., 2014, 2012b; Verdoux et al., 1999; Wigman et al., 2014, 2013; Yung et al., 2006a). The co-presence of psychotic symptomatology in anxiety and depressive disorders is common (e.g. Yung et al., 2007a, 2006a) and it has been suggested that their accumulating comorbidity can impact on prognosis in clinical samples, in an effect known as Berkson's bias (Maric et al., 2004). The presence of psychotic experiences has also been shown to increase the risk of suicidal ideation and suicidal behaviours among depressed adolescents (Kelleher et al., 2014, 2013), suggesting that psychotic experiences may be a marker of particular severity in this population. Furthermore, psychotic experiences have also been associated with help-seeking behaviour, with subclinical experiences of thought-control, paranoia or strange experiences doubling the odds of attending a GP for emotional problems compared to individuals with no psychotic symptoms (Murphy et al., 2012). In the same study, paranoia was linked to an almost threefold increase in receiving counselling or therapy while multiple psychotic experiences were shown to have a cumulative effect on the odds of seeking help. These findings have been replicated elsewhere (DeVylder et al., 2014) and similar findings have been shown specifically for persecutory ideas (Armando et al., 2012). In Murphy et al.'s (2012) study, the strongest predictor of help-seeking was common mental disorder but the authors report that psychotic experiences also predict help-seeking exists independently of this. Contrasting findings have been reported by Kobayashi et al. (2011) who found that common mental disorder appeared to mediate this association among clinical help-seekers and students in Japan. In addition, evidence from a Swiss community study suggests that symptoms of anxiety and depression may be the most prominent reason for individuals with psychotic experiences to seek help (Schultze-Lutter et al., 2013a). Together, these findings suggest that common mental disorders could play a key role in the relationship between psychotic experiences and need for care, although this remains to be clarified.

Shining the spotlight on South London

A recent community morbidity survey was conducted on a representative general population sample in the South London boroughs of Southwark and Lambeth (South East London Community Health: SELCoH; Hatch et al., 2011). This is an area with a high concentration of risk factors for psychosis, including a high proportion of migrants and ethnic minorities, and high levels of exposure to urbanicity, deprivation, trauma and stressful life

events, and drug use (Hatch et al., 2012, 2011; Morgan et al., 2014). Using data from SELCoH, Morgan et al. (2014) have reported a one-year prevalence for psychotic experiences of 18%, as measured by the Psychosis Screening Questionnaire (PSQ; Bebbington and Nayani, 1995). Despite the high prevalence, partly attributable to the relatively liberal method of measurement used (see Appendix A), Morgan and colleagues demonstrated that psychotic experiences in this sample were associated with a number of risk factors for psychosis, including younger age, ethnic minority status, lower education, lack of employment, recent cannabis use, childhood trauma and stressful life events. Nevertheless, the clinical relevance of these experiences was not investigated. In particular, it is not clear to what extent these psychotic experiences were related to impaired daily functioning, help-seeking behaviour or suicidality (which has also been shown to be high within this sample; Aschan et al., 2013). Furthermore, in line with previous findings, Morgan and colleagues reported a strong association between psychotic experiences and common mental disorder, with a five-fold increase in the odds of reporting psychotic experiences among those with a common mental disorder compared to those without (OR = 4.99, 95% CI: 3.75 to 6.62). Therefore, the aim of the present chapter is to build on the recent work by Morgan at al. (2014) by investigating the clinical impact of psychotic experiences measured with the PSQ and examining the extent to which this is explained by concurrent common mental disorder.

Based on previous research, the following hypotheses were tested:

- H_0 *Subclinical psychotic experiences in the general population will not be associated with impairment, help-seeking or suicidality*
- H_1 Those who report psychotic experiences will show more daily impairment than those who do not, but only in the context of common mental disorder
- H_2 Those who report psychotic experiences will report more clinical help-seeking than those who do not, but only in the context of common mental disorder
- H_3 Those who report psychotic experiences will report more suicidality than those who do not, but only in the context of common mental disorder

3.2 Method

Data were collected as part of the Biomedical Research Council South East London Community Health study (SELCoH). SELCoH was a population-based household survey of physical and psychiatric morbidity conducted between June 2008 and December 2010 in the two London boroughs of Lambeth and Southwark. These two boroughs are socioeconomically diverse, containing high levels of deprivation compared to other areas in the UK but with some pockets of relative wealth. The area has an ethnically diverse population too, with a greater

proportion of individuals from Black Caribbean and Black African ethnic backgrounds than other areas of London, but fewer individuals from Asian backgrounds (Office for National Statistics, 2013). Full details of the design, purposes and methods of SELCoH are described by Hatch et al. (2012, 2011), along with some primary descriptive outcomes. Elements relevant to this PhD are outlined below.

3.2.1 Study design, sample and procedure

SELCoH used a cross-sectional study design to gather data about physical and mental health from individuals in a community setting. In brief, a random sample of households within the catchment area was identified using the UK Small User Postcode Address File (PAF), which has near complete coverage of private households (defined as one person or group of people who have the accommodation as their only or main residence and for groups who either share at least one meal a day or share the living area) and excludes addresses receiving over 50 pieces of mail per day. Introductory letters were sent to all selected households, which were then visited up to four times at different times of the day and week, and when contact was made informed consent was sought from as many eligible members of the household as possible. All members of the household aged 16 years or over were eligible to participate.

Interviews were carried out face to face by trained interviewers, usually in the participants' homes. Structured assessments were administered with the assistance of laptop computers. This allowed controls to be placed on data input and sped up the data entry process, making the data more reliable. Data was collected on basic demographics, socioeconomic status, physical and mental health symptoms, treatment and health service use, substance use, social adversity and psychosocial resources. Rather than exclude potential participants based on language, translators were employed to assist with interviews where participants were non-English speakers.

Ethical approval was received prior to the start of the study from King's College London Research Ethics Committee (CREC/07/08-152).

3.2.2 Key measures

SELCoH based much of their interview upon the methodology of the Adult Psychiatric Morbidity Survey of England 2007 (McManus et al., 2009) and included many of the same sociodemographic and socioeconomic variables, as well as other environmental factors. In particular, this included details about ethnicity, marital status, current employment and social class, education achieved to date, and lifetime use of cannabis. Other key outcome measures are described in more detail below.

Psychotic experiences

The Psychosis Screening Questionnaire (PSQ; Bebbington and Nayani, 1995) was used to elicit information on psychotic experiences. The design, rationale and administration of this measure are described in detail in Appendix A. Briefly, the PSQ is an interviewer administered questionnaire that assesses psychotic experiences in the preceding year and comprises five sections covering hypomania, thought disorder, paranoia, strange experiences and hallucinations. Each section has an initial probe, followed by secondary questions which are designed to establish the psychotic quality of experiences. The PSQ has been validated in two national surveys in the UK (Nazroo, 1997; Singleton et al., 2003). Following previous studies (e.g. Morgan et al., 2009), the analyses presented here primarily compare individuals who reported one or more psychotic experience on the PSQ with those who did not. Since the aim was to be inclusive and to identify any psychotic experiences that might be associated with distress and help-seeking, this was defined as endorsing the first key question in each category. As we were specifically interested in psychotic experiences, items related to hypomania were discarded. This method is consistent with Morgan et al. (2014).

Common mental disorder

Common mental disorder was assessed using the revised Clinical Interview Schedule (CIS-R; Lewis et al., 1992). The CIS-R is designed for use by lay interviewers and has thus been popular among large community samples (Jenkins et al., 2003). It specifically asks participants to provide information about their mental health within the preceding week, thus providing a relatively reliable snapshot of the individual's psychiatric morbidity. As with the PSQ, the analyses presented here primarily compare those who reported symptoms of common mental disorder and those who did not.

Social and functional impairment

No formal measure of functioning was included in the SELCoH assessment battery that dealt specifically with mental health problems. Therefore, individual items from other scales were used as indicators of social and functional impairment. Social impairment was indexed using an item from the CIS-R, in which participants indicated how their emotional health was affecting their social activities. This was recoded as a binary variable to indicate one or more social activities stopped in the past week. Functional impairment was indexed using two items from the 12-item Short Form questionnaire (SF-12; Ware et al., 1996), a self-report scale that assesses the impact of current physical and mental health. One item asked whether participants had accomplished less than they would like in their work or daily activities due to

their emotional health. The other item asked whether they performed these daily tasks and work activities with less care compared to usual, again due to their emotional health. These were binary variables coded as present if the item was endorsed for at least “quite a bit” of the time in the preceding four weeks.

Help-seeking and suicidality

Help-seeking was defined broadly and inclusively as contacting a professional health service “about being anxious or depressed or [about] a mental, nervous or emotional problem” in the previous 12 months. In addition, participants were asked about help sought from informal sources of support, such as friends, family or religious/spiritual leaders. Participants were also specifically asked if they had “ever been seen by a counsellor, psychotherapist, clinical psychologist or other therapist for a ‘talking therapy’”. This was recoded to identify individuals who had received any talking therapy within the previous year (estimated from the date of interview and the date last seen by therapist).

Suicidality was recorded in terms of lifetime suicidal ideation (feeling life isn’t worth living, wishing to be dead or thinking about taking own life without real intention) and suicide attempts, and then specifically whether these were present in the last year.

3.2.3 Statistical analysis

Sample characteristics were described and the prevalence of psychotic experiences and common mental disorder was presented. The overlap between psychotic experiences and common mental disorder was examined and the cross-tabulation was used to form four morbidity groups: no symptoms, psychotic experiences only, common mental disorder only, and both psychotic experiences and common mental disorder. These groups were used in subsequent analyses.

Logistic regression analyses were used to explore associations between psychotic experiences and indicators of impairment and distress, namely social and functional impairment, help-seeking and suicidality. For significant associations, analyses were then stratified in order to examine the impact of psychotic experiences inside and outside the context of common mental disorder. Analyses are presented as odds ratios, both unadjusted and adjusted for potential confounders. Age, sex and ethnicity were included as a priori confounders each time. Separate chi-squared tests and correlation analyses were conducted to identify additional confounders for each analysis (not reported). Variables that were associated with both psychotic experiences and the outcome of interest were included in the logistic regression model as potential confounders.

All analyses were conducted using Stata version 11. Weights were applied using Stata's survey set command to weight for non-response and take account of clustering by household. As such, all percentages and analyses are weighted. Since these analyses were intended as a pilot to develop hypotheses for the present study, no adjustments were made for multiple testing.

3.3 Results

3.3.1 Sample characteristics

In total, 2,070 private households were contacted, of which 1,075 (51.9%) had at least one member who agreed to participate. Of the 2,359 eligible individuals within these households, 1,698 (71.9%) agreed to be interviewed (mean number of participants per household 2.7, *SD* = 1.2). The sample was broadly representative of the catchment area population in terms of basic demographic and socio-economic characteristics (see Morgan et al., 2014: online Table DS1). PSQ data was missing for 10 participants and 8 who reported having a current or past diagnosis of psychosis were excluded from the analyses presented here, giving a sample of 1,680. There were slightly more females than males (female n = 946, 56%) and the mean age was 39 years (*SD* = 16.9), slightly older than the highest risk period for psychosis.

Psychotic experiences and common mental disorder

As previously reported by Morgan et al., 315 individuals reported one or more psychotic experience in the preceding 12 months, defined as a positive response to a secondary probe on the PSQ, giving a one year weighted prevalence of 17.9% (95% confidence interval: 16.0% to 19.9%). Individual item responses are shown in Table 3.1; paranoia was the most commonly reported experience (*n* = 221; 12.4% weighted). In comparison, 448 individuals were classified as having a common mental disorder, defined as a score 12 or above on the CIS-R, giving a weighted prevalence of 27.3% (95% CI: 25.0% to 29.8%).

Table 3.1 PSQ item response summary for SELCoH I

PSQ symptom categories *Initial probe* **Key questions**	'Yes' Responses *n* (%)	*(weighted %)*
Hypomania		
1A Over the past year, have there been times when you felt very happy indeed without a break for days on end?	865 (51.4)	*(50.6)*
1B Was there an obvious reason for this?	510 (30.3)	*(29.4)*
1C Did your relatives or friends think it was strange or complain about it?	**56 (3.3)**	***(3.1)***
Thought insertion		
2A Over the past year, have you ever felt that your thoughts were directly interfered with or controlled by some outside force or person?	128 (7.6)	*(7.4)*
2B Did this come about in a way that many people would find hard to believe, for instance through telephony?	**20 (1.2)**	***(1.1)***
Paranoia		
3A Over the past year, have there been times when you felt that people were against you?	371 (22.1)	*(21.0)*
3B Have there been times when you felt that people were deliberately acting to harm you or your interests?	**221 (13.1)**	***(12.4)***
3C Have there been times when you felt that a group of people was plotting to cause you serious harm or injury?	**54 (3.2)**	***(2.9)***
Strange experiences		
4A Over the past year have there been times when you felt that something strange was going on?	267 (15.9)	*(15.1)*
4B Did you feel it was so strange that people would find it very hard to believe?	**99 (5.9)**	***(5.7)***
Hallucinations		
5A Over the past year, have been times when you heard or saw things that other people couldn't	126 (7.5)	*(7.4)*
5B Did you at any time hear voices saying quite a few words or sentences when there was no-one around that might account for it?	**64 (3.8)**	***(3.9)***

As previously reported, psychotic experiences and symptoms of common mental disorder tended to occur in combination more often than would be expected by chance. Among those with a common mental disorder 36% reported psychotic experiences, compared with only 11% of those without a common mental disorder: OR = 4.64, 95% CI: 3.52 to 6.12, $p < .001$. The distribution of psychotic experiences and common mental disorder alone and in combination is shown for the whole sample in Figure 3.1.

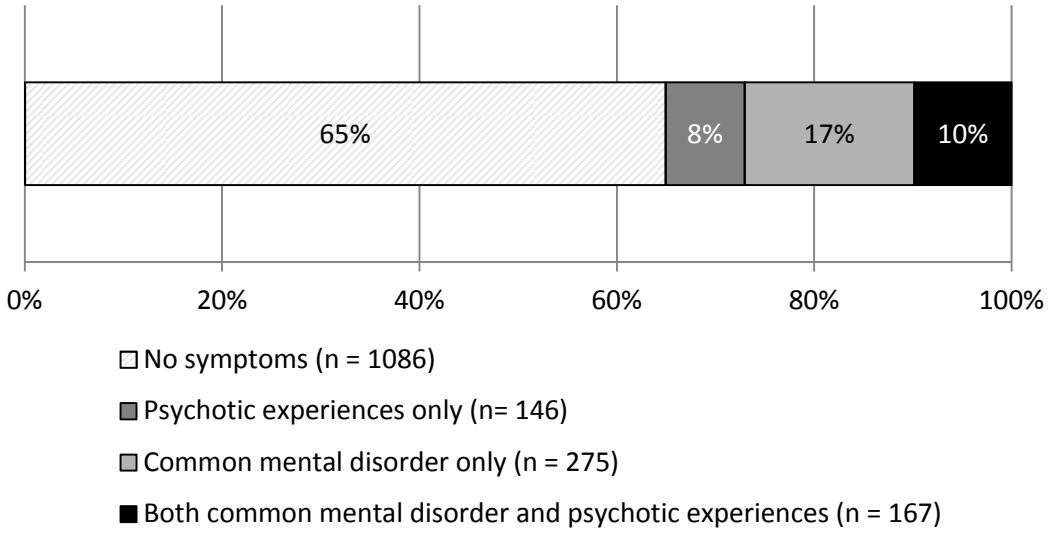


Figure 3.1 Weighted distribution of common mental disorder and psychotic experiences (*n* = 1674)

Both psychotic experiences and common mental disorder were associated with unemployment, past year cannabis use, educational achievement below degree level and being single (not shown). These variables were therefore treated as potential confounders and considered for use in subsequent analyses.

3.3.2 Clinical impact of psychotic experiences

Psychotic experiences and self-reported functional impairment

Across the whole sample, functional impairment was reported by a minority of individuals, with 13% (*n* = 200) reporting impairment in social activities, 18% (*n* = 294) reporting less accomplishment and 16% (*n* = 257) taking less care over their daily activities. As predicted, the presence of psychotic experiences was associated with greater odds of social impairment [OR = 3.50, 95% CI: 2.50 to 4.90], lower daily accomplishment [OR = 4.38, 95% CI: 3.27 to 5.86] and reduced care in daily activities: OR = 4.30, 95% CI: 3.15 to 5.86.

Logistic regression analyses stratified by the presence of common mental disorder revealed that psychotic experiences without common mental disorder were not significantly associated with daily functional impairment (see Table 3.2). In contrast, among those with a common mental disorder, the presence of psychotic experiences was associated with a two- to threefold increase in the odds of self-reported functional impairment: Adjusted ORs 2.02 to 3.00, 95% CIs: 1.28 to 4.25. Adjustment for confounders had little impact on the strength of these associations.

Psychotic experiences and help-seeking

Just under half of the sample (45.6%, *n* = 744) reported no psychological or emotional problem at all in the previous 12 months and were thus removed from the help-seeking analyses. Of the remaining 943 individuals, 574 (66%) had sought help from any informal source in the preceding year, 281 (30%) had sought help from any health professional and 89 (9%) had received talking therapy. As predicted, there was no significant association between psychotic experiences and informal help-seeking [OR = 1.01, 95% CI: 0.72 to 1.41]. However, those who reported psychotic experiences did have significantly greater odds of having sought professional help in the past year: OR = 1.60, 95% CI: 1.16 to 2.20. Similarly, psychotic experiences were associated with a significant increase in the odds of having received talking therapy in the past year: OR = 1.93, 95% CI: 1.20 to 3.10.

Table 3.3 shows analyses stratified by common mental disorder. Those who reported psychotic experiences without common mental disorder were not significantly more likely to seek professional help or to receive talking therapy in the last year. Among those with a common mental disorder, the presence of psychotic experiences was statistically associated with a 70% increase in the odds of seeking professional help: Adj OR = 1.70, 95% CI: 1.08 to 2.67. Adjustment for confounders had minimal effect on this association. There was also tentative evidence of a similar association between psychotic experiences and talking therapy [Adj OR = 1.75, 95% CI: 0.94 to 3.28], but because this outcome was rarer there was insufficient statistical power to confident that this was a true effect.

Psychotic experiences and suicidality

Suicidal outcomes in the sample were rare. Around 20% of the sample (*n* = 342) reported experiencing lifetime suicidal ideation and just under a quarter of these had done so within the previous year (*n* = 83, 5% of the total sample). Just under 8% of the sample reported having ever attempted suicide (*n* = 122), including eight in the previous year (0.5% of the total sample).

Table 3.2 Association between psychotic experiences and self-reported functional impairment, stratified by common mental disorder

Nature of impairment		Impaired	Unadjusted			Adjusted†		
Stratification	*PE reported*	*n* (%)	OR	(95% CI)	*p*	OR	(95% CI)	*p*
Social activities (N = 1674)								
No common mental disorder	*PE -*	41 (4.2%)	1.00	-		1.00	-	
	PE +	4 (3.7%)	0.87	(0.29-2.60)	.805	1.08	(0.35-3.37)	.893
Common mental disorder	*PE -*	76 (29.5%)	1.00	-		1.00	-	
	PE +	**76 (45.7%)**	**2.00**	**(1.32-3.06)**	**.001**	**2.02**	**(1.28-3.18)**	**.003**
Accomplishment of work/daily activities (N = 1665)								
No common mental disorder	*PE -*	69 (6.5%)	1.00	-		1.00	-	
	PE +	13 (11.4%)	1.84	(0.95-3.59)	.072	1.72	(0.86-3.45)	.126
Common mental disorder	*PE -*	109 (40.8%)	1.00	-		1.00	-	
	PE +	**103 (65.8%)**	**2.79**	**(1.82-4.27)**	**<.001**	**3.00**	**(1.92-4.68)**	**<.001**
Care taken in work/daily activities (N = 1666)								
No common mental disorder	*PE -*	48 (4.7%)	1.00	-		1.00	-	
	PE +	11 (7.4%)	1.62	(0.80-3.28)	.180	1.87	(0.92-3.82)	.086
Common mental disorder	*PE -*	103 (38.7%)	1.00	-		1.00	-	
	PE +	**94 (60.3%)**	**2.40**	**(1.58-3.66)**	**<.001**	**2.71**	**(1.73-4.25)**	**<.001**

Note: All percentages are weighted. PE = psychotic experiences

† Adjusted for age, sex, ethnicity and unemployment

Table 3.3 Association between psychotic experiences and help-seeking, stratified by common mental disorder

Help-seeking in last year		Help-seeking	Unadjusted			Adjusted†		
Morbidity group	*PE reported*	*n* yes(%)	OR	(95% CI)	*p*	OR	(95% CI)	*p*
Any professional help-seeking (n = 932)								
No common mental disorder	*PE -*	101 (23.4%)	1.00	-		1.00	-	
	PE +	14 (17.7%)	0.71	(0.37-1.34)	.286	0.81	(0.42-1.53)	.509
Common mental disorder	*PE -*	89 (35.6%)	1.00	-		1.00	-	
	PE +	**75 (47.8%)**	**1.66**	**(1.09-2.53)**	**.019**	**1.70**	**(1.08-2.67)**	**.022**
Any talking therapy (n = 929)								
No common mental disorder	*PE -*	26 (5.9%)	1.00	-		1.00	-	
	PE +	6 (7.0%)	1.19	(0.47-3.00)	.713	1.26	(0.51-3.08)	.615
Common mental disorder	*PE -*	29 (11.8%)	1.00	-		1.00	-	
	PE +	27 (17.8%)	1.62	(0.89-2.92)	.111	1.75	(0.94-3.28)	.078

Note: All percentages are weighted. PE = psychotic experiences

† Adjusted for age, sex, ethnicity and unemployment

Table 3.4 Association between psychotic experiences and suicidality, stratified by common mental disorder

Type of suicidality		Suicidality	Unadjusted			Adjusted†		
Morbidity group	*PE reported*	*n* yes (%)	OR	(95% CI)	*p*	OR	(95% CI)	*p*
Lifetime suicidal ideation (N = 341)								
No common mental disorder	*PE -*	135 (12.1%)	1.00	-		1.00	-	
	PE +	27 (17.8%)	1.57	(0.98-2.52)	.062	**1.64**	**(1.02-2.64)**	**.042**
Common mental disorder	*PE -*	88 (32.6%)	1.00	-		1.00	-	
	PE +	**91 (54.8%)**	**2.50**	**(1.65-3.79)**	**<.001**	**2.54**	**(1.65-3.93)**	**<.001**
Past year suicidal ideation (N = 83)								
No common mental disorder	*PE -*	18 (1.6%)	1.00	-		1.00	-	
	PE +	4 (2.4%)	1.58	(0.51-4.90)	.431	1.53	(0.48-4.84)	.472
Common mental disorder	*PE -*	29 (11.1%)	1.00	-		1.00	-	
	PE +	**32 (19.5%)**	**1.95**	**(1.09-3.47)**	**.024**	**1.96**	**(1.06-3.62)**	**.031**
Lifetime suicide attempts (N = 121)								
No common mental disorder	*PE -*	40 (4.0%)	1.00	-		1.00	-	
	PE +	6 (4.2%)	1.06	(0.43-2.61)	.895	1.20	(0.50-2.90)	.689
Common mental disorder	*PE -*	32 (13.1%)	1.00	-		1.00	-	
	PE +	**43 (26.6%)**	**2.40**	**(1.39-4.15)**	**.002**	**2.67**	**(1.49-4.78)**	**.001**

Note: All percentages are weighted. PE = psychotic experiences

† Adjusted for age, sex, ethnicity and unemployment

Psychotic experiences were significantly associated with around a threefold increase in odds for all suicidal outcomes: lifetime suicidal ideation [OR = 3.13, 95% CI: 2.35 to 4.17], past year suicidal ideation [OR = 3.64, 95% CI: 2.25 to 5.88] and lifetime suicide attempts [OR = 3.17, 95% CI: 2.11 to 4.76]. There was a similar trend for past year suicide attempts [OR = 3.56, 95% CI: 0.86 to 14.82]; however, the number of individuals attempting suicide in the past year was too small to achieve sufficient statistical power.

Stratified analyses are displayed in Table 3.4. Psychotic experiences in isolation were not associated with significantly increased odds of lifetime suicide attempts or past year suicidal ideation, but did show a marginal increase in the odds of reporting lifetime suicidal ideation which was statistically significant after adjustment for confounders: Adj OR = 1.64, 95% CI: 1.02 to 2.64. In the context of common mental disorder, the presence of psychotic experiences was statistically associated with a twofold increase in the odds of reporting past-year suicidal ideation [Adj OR =1.96, 95% CI: 1.06 to 3.62] and a two- to threefold increase in the odds of reporting lifetime suicidal ideation [Adj OR = 2.54, 95% CI: 1.65-3.93] and suicidal experiences: Adj OR = 2.67, 95% CI: 1.49 to 4.78. Adjustment for confounders again made minimal difference to the strength of associations.

3.4 Discussion

This chapter aimed to investigate the clinical relevance of psychotic experiences in the general population. As hypothesised, psychotic experiences were associated with increased odds of self-reporting (1) impaired social and daily functioning (odds ratios 4 to 5), (2) help-seeking from professional sources (odds ratios 1 to 2) and (3) lifetime or past year suicidality (odds ratios 3 to 4). However, stratified analyses revealed that these associations occurred almost exclusively in the context of common mental disorder, again in line with my hypotheses. Individuals reporting psychotic experiences without common mental disorder were not significantly different from 'healthy' individuals on these measures. Among those with common mental disorder, the presence of psychotic experiences was associated with (1) two- to threefold greater odds of self-reported social and daily functional impairment, (2) just under a twofold increase in the odds of professional help-seeking, and (3) around a two- to threefold increase in the odds of reporting suicidality. In all, the cumulative presence of psychotic experiences and common mental disorder appeared to show the greatest need for care based on the features measured.

Methodological limitations

It is important to acknowledge a number of limitations with these findings. Firstly, as with all epidemiological surveys, the impact of nonparticipation may be a concern. Although

participation rates were good at the individual level (72%), participation in SELCoH at the household level (52%) was lower than seen in other similar surveys (Jenkins et al., 2003). The potential impact of selection bias on the results cannot be excluded. In particular, those experiencing mental health problems may be less likely to participate in research studies (Knudsen et al., 2010). Nevertheless the same study showed this to have important implications for prevalence estimates but little impact on tests of association between exposures and outcomes. Morgan et al. (2014) note that since the SELCoH sample appears to have a high prevalence of psychotic experiences already, and is broadly representative of the local population on core demographic characteristics, the impact of selection bias is likely to be minimal. Regarding information bias, data were collected retrospectively, opening up the possibility of recall bias. In addition, data relied on self-report, which could be affected by social desirability (particularly for psychotic experiences; DeVylder and Hilimire, 2014) or exaggerated (in terms of impact on functioning). However, interviews were conducted by trained interviewers and participants were not informed of the study's hypotheses, so again the impact of this bias should hopefully be minimal.

Critically, the data presented in this chapter are cross-sectional and as such causality cannot be inferred. For example, depression may lead to functional impairment, but the reverse is also plausible. In the present study this is exacerbated firstly by the differing timeframes assessed by each measure. In particular, common mental disorder and functioning are measured in relation to the last week, psychotic experiences and help-seeking with reference to the last year, and suicidality is assessed for lifetime. This may have led to an underestimation of the association between psychotic experiences (which are often transient) and functioning, for example, since the experiences may have remitted weeks or months before functioning was measured. Nonetheless, depression is often preceded by (and has been shown to predict) other depression (Keenan et al., 2009). Moreover, the strength of association between past-week common mental disorder and past-year help-seeking, or lifetime suicidality, encourages the assumption that common mental disorder may extend beyond the time period measured. Nevertheless, these findings should be interpreted with caution. Secondly, the lack of specificity with regards to help-seeking means that it is not possible to tell what complaint has led an individual to seek help. Importantly, it is not known whether the greater odds of help-seeking among those who experience both common mental disorder and psychotic experiences is driven by the former or the latter (although previous evidence from Schultze-Lutter et al. (2013a) would suggest the former). Future studies that can better establish the temporal relationship between these factors are required in order to improve on these conclusions.

Finally, the analyses presented in this chapter were conducted on secondary data and were not the main aim of data collection. Therefore the reliability and validity of some measures may not be ideal. In particular, the use of the PSQ (or any psychosis screening tool) to measure psychotic experiences in the general population is problematic. The PSQ was designed to be a brief and basic screening tool to be followed up with a more detailed assessment but has since been re-purposed as a measure of psychotic experiences (see Appendix A). Consequently, the PSQ does not account well for the context in which experiences occur and may be likely to overestimate the prevalence of psychotic experiences as a result of misinterpretation, for example by categorising genuine threat and persecution as a subclinical paranoid delusion (Morgan et al., 2014). However, psychotic experiences assessed on the PSQ are associated with the same variables as psychotic disorder, consistent with the idea that it may validly identify experiences that are phenomenologically continuous. Nevertheless, the PSQ examines only a narrow range of positive symptoms and there is no information about the relative severity, frequency or duration, which may be particularly important when assessing clinical relevance. A future study using broader and more detailed assessments would capture a more complete picture.

The clinical relevance of psychotic experiences

The above limitations notwithstanding, the findings presented here appear to indicate that while the presence of psychotic experiences is associated with several indices of need for care in the general population, much of this is explained by the presence of concurrent common mental disorder. There are two important aspects to this. The first is that psychotic experiences which occur in absence common mental disorder appear to have little clinical impact (based on the measures examined here), suggesting that the additional presence of common mental disorder may be the key factor in determining the presence of a need for care. This is consistent with findings that psychotic experiences are not necessarily distressing in themselves (e.g. Brett et al., 2014; Johns et al., 2014; Peters et al., 1999). In general, psychotic experiences were associated with a slight but non-significant increase in the odds of each of the outcomes (and a significant increase for lifetime suicidal ideation) when a common mental disorder was not present. However, the absence of a common mental disorder does not necessarily mean that subjects were completely free of depressive/anxious symptoms, but rather that they did not meet the cut-off denoted by the CIS-R. It is therefore possible that the slightly greater odds of need for care among the group with psychotic experiences alone could also be explained by the additional presence of some degree of common mental disorder.

The second aspect is that when individuals do have a common mental disorder, their odds of reporting impairment, seeking professional help and reporting suicidality are substantially increased by the additional presence of psychotic experiences. This is consistent with the idea that psychotic experiences may be markers of psychopathological severity within common mental disorders (Kelleher et al., 2014, 2012b). However, this could also be driven more by psychotic phenomena. Depression has been thought of as a dimension of psychotic disorder (van Os and Kapur, 2009) and has been shown to be present frequently in the psychosis prodrome and UHR state (Addington et al., 2011; Yung et al., 2004). A recent meta-analysis of 1683 UHR subjects estimated the baseline prevalence of depressive and anxiety disorders within the UHR group to be around 41% and 15% respectively (Fusar-Poli et al., 2014b). Conversely, psychotic experiences have also been shown to convey a risk for nonpsychotic disorder (Kaymaz et al., 2012). One impact of common mental disorder may be to impair the coping strategies of individuals with psychotic experiences (Fusar-Poli et al., 2014b), meaning that psychotic experiences may cause more difficulty and distress when cognitive resources are taken up with common mental disorder. Furthermore it has been suggested that the relationship between coping and psychotic experiences may be bidirectional (Lin et al., 2011), leading to exponentially increasing difficulty. Temporally, it is not possible to tell which symptoms predated others in this particular sample. However, other research has suggested that although symptoms co-occur they do not predict one another over time (Wigman et al., 2011). Regardless, morbidities may accumulate and lead to further problems (Fusar-Poli et al., 2014b). Moreover, a recent MRI study has suggested that depressive disorders may also significantly impact on the neurobiology of UHR subjects (Modinos et al., 2014). In all, psychotic experiences identified in the context of common mental disorder may therefore represent those most comparable to clinical samples.

The findings presented here are mostly in line with previous findings. Psychotic experiences have been shown to be associated with lower socio-occupational functioning independently of common mental disorder (Kelleher et al., 2014). The finding that psychotic experiences were not associated with help-seeking outside of common mental disorder is more supportive of Kobayashi et al. (2011) than of more recent studies (DeVylder et al., 2014; Murphy et al., 2012). However, the present findings have shown a small association between psychotic experiences and help-seeking among those with a common mental disorder, which tentatively supports the findings of these latter studies. One possible explanation might be the way in which psychotic experiences have been measured. For example the method of assessment used in the present study (and by Morgan et al., 2014) was more liberal (prevalence 18%) than that of Murphy et al. (see Appendix A). Likewise the prevalence rate

reported by Kobayashi et al. is 10% in the community, compared to DeVylder et al.'s prevalence of 3.4%. It may therefore be that psychotic experiences identified by a more stringent threshold (which may be more severe) are more likely to be associated with help-seeking independently, while softer expressions of this phenotype are more dependent on common mental disorder. Finally, in terms of suicidality, the finding that psychotic experiences were associated with suicidal ideation and attempts among individuals with common mental disorder echoes findings by Kelleher et al. (2014, 2012c). The odds ratios reported in the present study are slightly lower (OR around 2) than those reported elsewhere for a community sample (ORs around 5; Kelleher et al., 2012c). However, the confidence intervals of the latter estimates are very wide and include the present estimates.

Together, these findings suggest that common mental disorder may be a vital part of the development of clinically relevant psychotic experiences. Accumulating common mental disorders and psychotic experiences may partly or wholly mediate the help-seeking feature that defines the UHR clinical population and, in this fashion, explain the marked impairment in psychosocial functioning that appears as a core feature of the UHR state, impacting on course and outcome (Fusar-Poli et al., 2014c). Whether cause or consequence, psychotic experiences might also be regarded as a marker of severity and particular need for care among those with a common mental disorder. However, more research is needed to replicate these findings, while addressing the present study's limitations, and to clarify this relationship between psychotic experiences and common mental disorder.

Conclusion and future work

Use of the SELCoH data offered a useful opportunity explore the psychotic experiences prevalent in the catchment area for the local UHR service, and thus the population of interest for this thesis. Nevertheless, there are a number of areas for improvement in future work. Firstly, the PSQ is not the best assessment tool for identifying individuals with clinically relevant psychotic experiences. It says nothing about the severity of particular experiences and assesses only a narrow range of positive symptoms. Using a broader, more clinically focused tool would help to improve this. Secondly, the study would also benefit from a more comparable measure of common mental disorder. In particular, one that refers to the same timeframe as the measure of psychotic experiences. Finally, a more focused assessment of help-seeking would allow for an exploration of what the help-seeking behaviour was in response to, and specifically what it is that drives the help-seeking among individuals with psychotic experiences. The rest of the thesis will attempt to make these improvements.

III. METHODOLOGY

CHAPTER 4 METHODS (1): DESIGN AND SAMPLE

4.1 Design

4.1.1 Study context

Data for this project were collected within the context of two larger research studies. Firstly, secondary data were available from the first round of the Biomedical Research Centre South East London Community Health study (SELCoH), collected between 2008 and 2010 (Hatch et al., 2011). Secondly, primary data collection was integrated within data collection for the Childhood Adversity and Psychosis Study (CAPsy) which collected data on a general population sample between 2011 and 2013. The relationship between these two studies is displayed in Figure 4.2. CAPsy is a study into first episodes of psychosis and its primary aims differed from those of the present study. However, there was significant overlap in the assessments that were included. Integration allowed for the streamlining of participant recruitment and access to additional data for the exploration of secondary hypotheses.

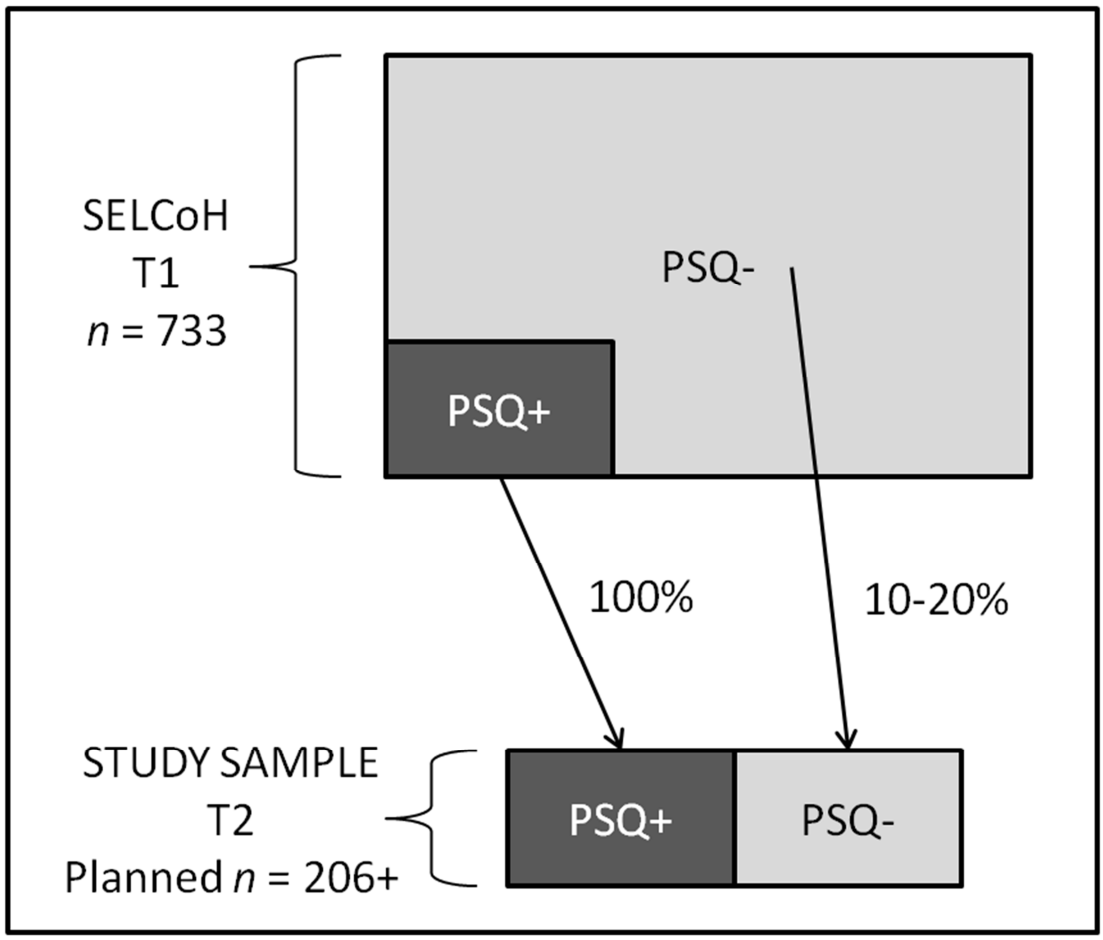
4.1.2 Ethical approval

Ethical approval for SELCoH was obtained from the King's College London Research Ethics Committee (CREC/07/08-152). Ethical approval for CAPsy was provided by the South London and the Maudsley NHS and Institute of Psychiatry Research Ethics Committee (Ref: 321/05, including amendments 1 to 9).

4.1.3 Study design

This PhD project is a cross-sectional study with a nested longitudinal sample. SELCoH I data had been collected prior to the start of this PhD project in 2011 and were available for analysis and follow-up. Subjects were selected for follow-up based on their responses to the Psychosis Screening Questionnaire (PSQ; described in Chapter 3, p.45 and Appendix A), which was included in the SELCoH I survey. My aim was to recruit 100% of those endorsing at least one symptom on the PSQ (and who met the inclusion criteria, defined below) and around 10-20% of those who endorsed no symptoms on the PSQ (as required for statistical power; see Figure 4.1). Since clinically relevant psychotic symptoms are relatively rare, enriching the sample in this way was intended to increase the statistical power of the study. Data gathered

from this sample could then be used to make prevalence estimates for the whole population (Duncan-Jones & Henderson, 1978; Pickles, Dunn, & Vázquez-Barquero, 1995).



Note: SELCoH T1 sample size estimated based on eligibility for present study (full SELCoH *N* = 1,690)

Figure 4.1 Planned study design using PSQ screening at time 1 in the SELCoH sample

In practice, however, the numbers that could be recruited were lower than expected, such that the SELCoH participants recruited at time 2 represented all those willing to take part, rather than a random sample. Additional subjects were therefore recruited in parallel to increase the sample size at time 2.

4.1.4 Interval between times 1 and 2

The interval between the start of SELCoH I and the start of SELCoH II was approximately 3 years. For those followed in the present study, the time interval calculated between interview dates was normally distributed around a mean of 2.8 years (*SD* = 0.67 years). The shortest time for follow-up was 1.4 years and the maximum time was 4.6 years. This was partly owing to the availability of participants and partly because of other factors, such as whether any changes of

address had taken place within this time, requiring additional work to be done in order to track participants down and maximise the follow-up.

4.2 Sampling

All subjects were recruited from within the London boroughs of Southwark and Lambeth. Two main sampling methods were used: subjects were either recruited by postal address (at times 1 and 2) or by GP practice (time 2 only). While each of these methods has advantages and disadvantages it is hoped that a combination of sampling approaches would mitigate any systematic bias that might result from the use of one method alone. This hypothesis is tested in Chapter 7. Furthermore, while it was theoretically possible that an individual could have been randomly selected by both methods, this did not actually occur.

Postal address sampling

A random sample of households within the catchment area was identified using a complete copy of the Small User Postcode Address File (PAF) as a sampling framework, which was purchased from the Post Office. The PAF has near complete coverage of private households in the UK and therefore is a good representation of the general population. All addresses in the catchment area were selected by filtering the relevant postcodes, and assigned a unique identifier number. Five per cent of the addresses (1000 addresses in total) were randomly selected using a random number generation method. Introductory letters were sent to all selected households, which were then visited up to four times at different times of the day and week, in order to maximise the chance of residents being at home and minimise sampling bias. When contact was made, residents were provided with written and verbal information, and informed consent was sought from as many eligible members of the household as possible. If all potential controls within the household refused, or no members were eligible, then the next address on the PAF list was visited. This method was used both by SELCoH at time 1 and independently by CAPsy at time 2.

This method has been shown to be epidemiologically rigorous and has produced a SELCoH I sample that was highly representative of census data for the same region (in terms of basic demographic measures) (Hatch et al., 2011). The SELCoH I survey itself achieved a household response rate of around 52%; this is lower than that reported by some other large surveys of the UK population (Jenkins et al., 2003). This may reflect the relatively high levels of socio-economic deprivation in Lambeth and Southwark, but in any event the sample was demographically representative. As with all surveys of this nature, there is still the potential for bias and therefore all results will be interpreted with caution.

Ninety four percent of SELCoH I participants gave permission to be followed up for future research and they were contacted to be re-interviewed for SELCoH II approximately three years later. During this process, eligible participants were given the information sheet for the present (thesis) study and encouraged to take part (as shown in Figure 4.2). At time 2, recruitment of eligible participants was limited to one per household, giving priority to those who screened positively on the PSQ at time 1 (because of their greater rarity).

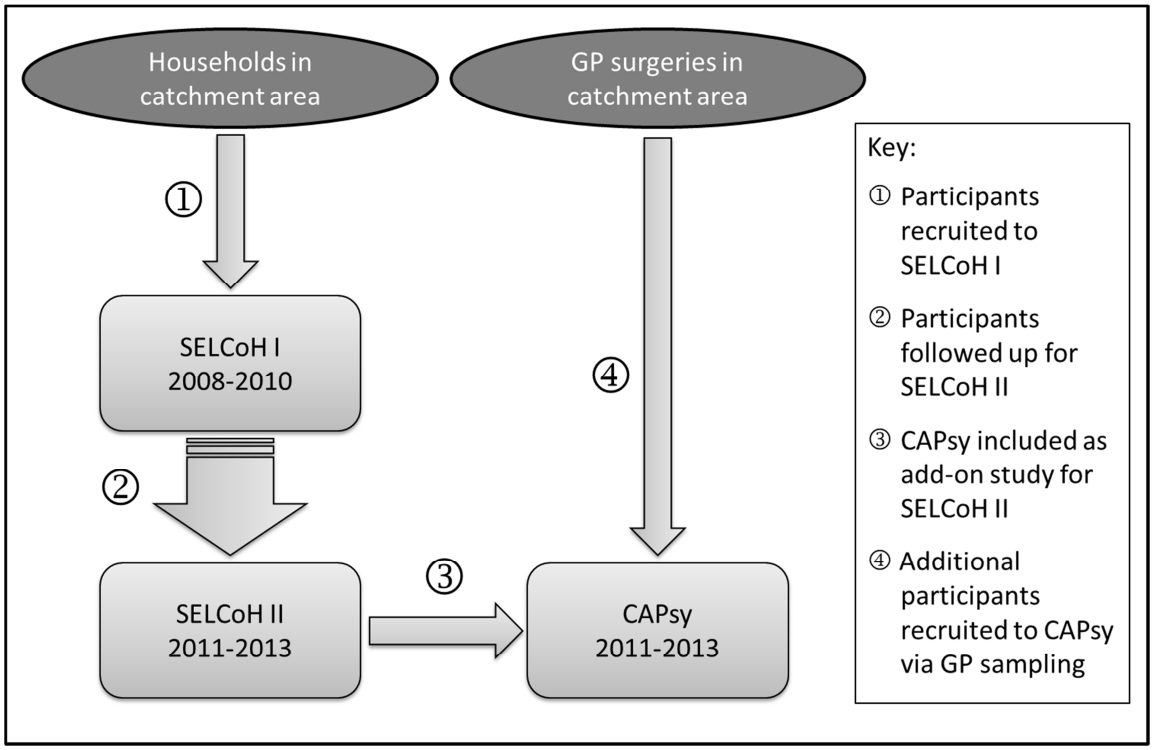


Figure 4.2 Flowchart showing the primary recruitment of participants to SELCoH and CAPsy

One hundred percent of the sample at time 1 and 46% of the sample at time 2 (n = 96) were recruited in total via use of the PAF. The original intention had been to recruit all participants through SELCoH because of the availability of existing data and thus the potential for a longitudinal sample, therefore this was the first source of recruitment explored and 43% of the total sample at time 2 (n = 89) were recruited as a follow-up to SELCoH II. An additional 3% (n =7) of the final sample were recruited directly by CAPsy using PAF sampling, without taking part in SELCoH. This is clarified in Figure 4.3.

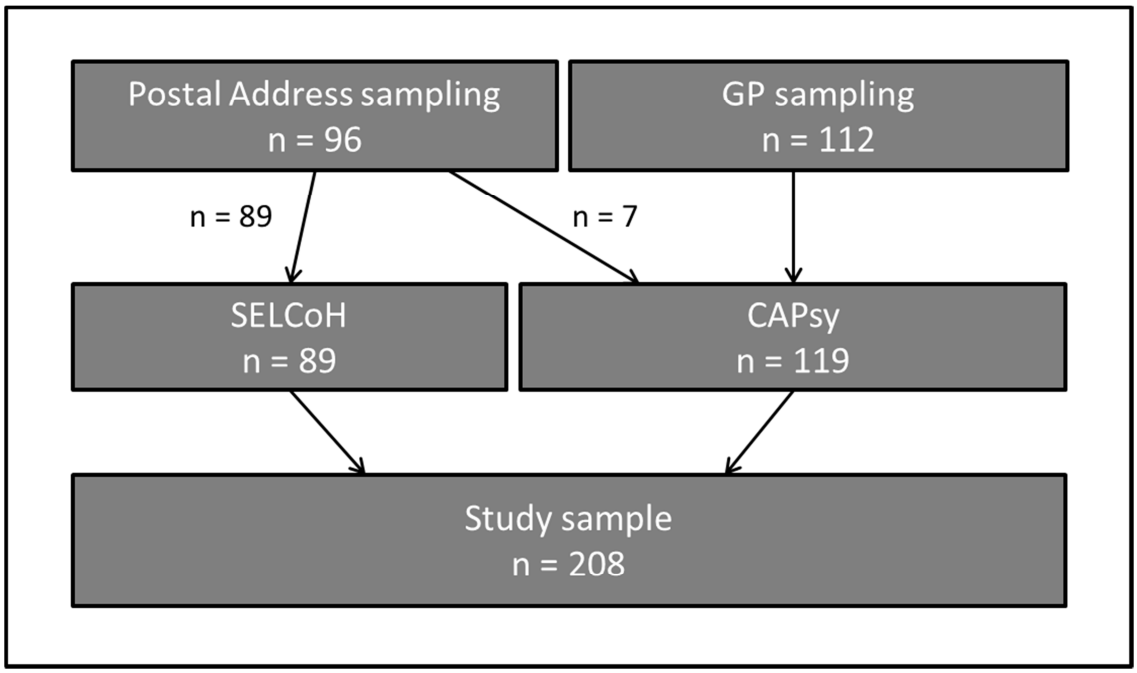


Figure 4.3 Recruitment of participants to the study sample

GP practice sampling

At time 2, additional subjects were recruited to the sample via GP patient lists. Approximately 97% of the population of Lambeth and Southwark is registered with a GP (based on data from Health & Social Care Information Centre, 2012). All GP surgeries in Lambeth and Southwark were contacted with the help of the Primary Care Research Network, and asked if they would be interested in assisting with recruitment of participants for the study. Of the surgeries that replied, 14 were randomly selected. Each month, one of the selected surgeries randomly selected 400 individuals from their lists who met the inclusion criteria (described below) and sent them each an invitation letter and an information pack. Clinical codes were used to remove those with a known psychotic disorder. If no reply was received after two weeks, a phone call was made or follow-up letter sent. Those who agreed were re-checked for eligibility and then invited in for an assessment. It was anticipated that 5% of individuals would respond, resulting in approximately 20 positive responses from each surgery. This method provided 52% (n = 108) of the cross-sectional sample at time 2.

4.2.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were defined such that they would be in line with some of the basic requirements for being eligible for referral to the OASIS clinical service. These were as follows:

- Age – between 18 and 35 years old at the time of interview. This corresponds with the age range eligible to seek help from the OASIS service.
- Psychiatric history – subjects were excluded if they had themselves received a psychotic diagnosis in the past or had been prescribed anti-psychotic medication. These are also exclusion criteria for the UHR state.
- Residency – subjects must have been resident in the London boroughs of Lambeth or Southwark at the time of first contact.
- Household – one subject was accepted per household. Since members of the same household are more likely to have shared both environmental and genetic exposures, accepting more than one person per household would have introduced a bias. While the households themselves had been randomly selected, the inclusion of a second individual from the same house would not have been truly random.

Participants were screened for inclusion criteria before being contacted. This was done either by the GP surgeries before sending out letters, or by the SELCoH research team before speaking with their participants about our study.

4.2.2 Sample size

The present study aims to define the prevalence of the UHR state in the general population. While several prevalence estimates have been reported for both psychotic disorders and subclinical psychotic experiences (e.g. Linscott and van Os, 2013; Perala et al., 2007; van Os et al., 2009, 2001), there has been very little published data pertaining to the prevalence of UHR in the community (see Chapter 2, p.33). Indeed, when the present study began no such studies had been published. In Chapter 2 I reviewed current research that has attempted to define the prevalence of the UHR state, highlighting that estimates have varied considerably according to the population examined and the criteria used, and that no study is directly comparable to the present study. Estimates based on PACE criteria (without functional decline) have been reported to be between 8% (Kelleher et al., 2012d) and 10% (Schimmelmann et al., 2011). However, the former estimate was based on a much younger sample than the present study (aged 11-13), while the latter was derived from a sample of just 58 individuals. Moreover, neither of these was able to provide a prevalence estimate for basic symptoms. Without appropriate comparison data a formal power calculation could not be

completed. In absence of this, a target sample size of around 200 was decided upon for reasons of feasibility.

4.3 Procedure

Individuals who expressed an interest in volunteering as a participant for CAPsy were invited to take part in a face to face interview with one of a team of trained researchers. Participants were told to expect the study to take around six hours to complete all the assessments. As a result these took place typically over three appointments, either in a test room at the Institute of Psychiatry or at another location of the participant's choosing if it was more convenient for them. This was generally in the participant's own home or at their workplace. Appointments at the Institute of Psychiatry were preferred because of the quiet environment and availability of desk space for note-taking. In these cases participants were provided with water to drink (or tea or coffee on request) and given opportunities to take breaks throughout the session if required. When appointments took place off-site the most appropriate room was identified in which the interview could take place most privately and with minimum distraction. This tended to also be wherever the participant felt most comfortable. The timing of appointments varied and appointments were arranged according to the availability and convenience of the participant. Since many individuals were in full time work, evening appointments were common and some also took place at weekends. For safety reasons, visits to off-site locations that had not been visited before were completed in pairs. Throughout CAPsy, interviews were conducted primarily by Kathryn Hubbard, Emma Palmer, Tjasa Velikonja, Charlotte Gayer-Anderson, Rachel Hepburn and myself.

At the initial appointment, prior to the interview, participants were given an information sheet to read. The aims and details of the study were explained to them and they were given the opportunity to ask questions. If they were happy to continue, participants were then taken through a consent form. This emphasised the confidentiality of the interview and the study's adherence to UK data protection laws. Interviewers were also required to ensure that participants understood their right to withdraw and their right to refuse to answer questions without giving a reason. This consent form was signed by both parties and kept on record, stored separately from the participant's data. Participants were reminded of these rights at the start of each subsequent appointment.

The interviews themselves were paper-based and comprised a combination of structured, semi-structured and self-completed assessments. The first appointment contained assessments central to the aims of CAPsy including assessments of psychotic experiences, and questions about trauma, life events and abuse past and present (not used in the present

thesis). This appointment tended to be the most intense for participants because of its sensitive questions and potentially distressing topics. Consequently, particular care was taken at the end of this session to make sure that participants felt ok and to remind them that all discussions would remain confidential. Researchers were also careful to show gratitude for their participation and to encourage them to return for the further appointments. The second and third appointments contained assessments about family history and substance use, along with the clinical assessments central to the research aims of this thesis. Genetic material was collected in the form of a blood or saliva sample where subjects were willing.

To encourage completion of all three appointments, participants were paid £50 in compensation for their time. This was paid in increasing instalments at the end of each appointment: £10 for completing the initial two hour appointment,£20 for the second two-hour appointment and a final £20 for the third appointment, which was often less than two hours (depending on what had not been completed in previous sessions). In addition, subjects who came to appointments at the Institute of Psychiatry were reimbursed for their travel expenses for two of the three appointments.

As mentioned previously, a small proportion of participants (n = 33, 16%) were recruited to the study sample directly without completing the full CAPsy. These subjects were seen in a single appointment lasting approximately two to three hours and containing only assessments relevant to the aims of the present study. These sessions took place in exactly the same way as the initial appointment described above and were all conducted by me. Participants completing the study in a single appointment typically received £20 compensation for their time. Later in the recruitment process, when recruitment numbers were lower than anticipated, participants were offered up to £40 to participate in order to encourage their participation. This applied only to those who had been part of the original SELCoH cohort and therefore whom there was baseline data available, in order to maximise the size of the longitudinal sample.

This face to face approach had several advantages. Firstly the inclusion of several semi-structured interviews within the assessment battery necessitated the use of interviewers rather than computerised questionnaires. Follow-up questions were able to clarify answers and to provide a greater depth of information. While the intimate and sensitive nature of the data collected could make it difficult for individuals to talk about, participants responded well to the face to face interview. Several mentioned that it was easy speaking with someone they didn't know, and this led to them giving frank and honest answers with minimal embarrassment. Participants are also likely to have got more from face to face interviews than they might have from a telephone interview. Despite not offering anything more than listening

to their answers, several participants compared the experience to a kind of therapy and found it cathartic. Others revealed that they had been able to share things during the appointment that they had never spoken about with anyone else.

The length of the appointments also necessitated this approach. Interviewers were responsible for keeping to time and ensuring that a sufficient amount of progress was made during each appointment so that the study could be completed. This minimised the amount of missing data, while the physical presence of a researcher may have reduced the likelihood of additional distractions, compared with subjects being left to complete assessments unsupervised. The most difficult aspect of this was organising the appointments themselves at times when the participants were available, which is likely to in part have led to having a smaller sample size than could have been reached for example by telephone. However, it can be argued that the methods used here have led to a higher quality of data collected than would have been achieved by other methods. The greater level of direct engagement with participants may encourage their participation in a follow up study or other future research.

CHAPTER 5 METHODS (2): MEASURES

5.1 Clinical measures: assessment of the ultra high risk state

As discussed in a previous chapter several assessments were available for identifying those at ultra high risk (UHR) of developing psychosis. The assessments were selected to correspond to those used in the OASIS service to maximise comparability between the clinical UHR sample and subjects meeting UHR criteria identified through this project.

For the identification of the UHR group the primary tool used was the Comprehensive Assessment for the At-Risk Mental State (CAARMS). At Risk Mental State is another term for the UHR state. The CAARMS is a semi- structured interview specifically designed for the assessment of help-seeking individuals against the Personal Assessment and Crisis Evaluation clinic's (PACE) criteria for the UHR state. It describes its aims as follows:

- *To determine if an individual meets the criteria for an 'At Risk Mental State'.*
- *To rule out, or confirm criteria for acute psychosis.*
- *To map a range of psychopathology and functioning factors, over time in young people at ultra high-risk of psychosis. (Yung et al., 2006b)*

The CAARMS comprises seven sections which cover various forms of psychotic experience along with other types of symptomatology that can be associated with an increased risk of psychosis (see Table 5.1). The PACE criteria are determined on the basis of the ratings in the first section of the CAARMS, which contains four subscales of positive symptoms: unusual thought content (such as ideas of reference), non-bizarre ideas (such as persecutory delusions), perceptual abnormalities (such as auditory hallucinations) and disorganised speech (subjective difficulties articulating thoughts and being understood). For each subscale, reported symptoms are given a global rating of severity (0-6) and a rating of frequency and duration (0-6), from which a simple algorithm is used to assess whether the individual meets UHR criteria. For full details please refer to the copy of the CAARMS included in Appendix B. Ratings are also made for the pattern of symptoms in relation to substance use and the subjective distress caused by the symptom (0-100). Participants were interviewed using the most up to date version of the CAARMS available at the time (Yung et al., 2006b). All subscales were included in the interview with the exception of 6.2 'Informant Reported or Observed Changes in Motor Functioning', since no informants were interviewed and participants were interviewed with the CAARMS only once.

Table 5.1 Structure of the CAARMS – sections and subscales

1: POSITIVE SYMPTOMS	6: MOTOR/PHYSICAL CHANGES
1.1 UNUSUAL THOUGHT CONTENT	6.1 SUBJECTIVE COMPLAINTS OF IMPAIRED MOTOR FUNCTIONING
1.2 NON-BIZARRE IDEAS	6.2 INFORMANT REPORTED OR OBSERVED CHANGES IN MOTOR FUNCTIONING
1.3 PERCEPTUAL ABNORMALITIES	6.3 SUBJECTIVE COMPLAINTS OF IMPAIRED BODILY SENSATION
1.4 DISORGANISED SPEECH	6.4 SUBJECTIVE COMPLAINTS OF IMPAIRED AUTONOMIC FUNCTIONING
2: COGNITIVE CHANGE ATTENTION/CONCENTRATION	7: GENERAL PSYCHOPATHOLOGY
2.1 SUBJECTIVE EXPERIENCE	7.1 MANIA
2.2 OBSERVED COGNITIVE CHANGE	7.2 DEPRESSION
3: EMOTIONAL DISTURBANCE	7.3 SUICIDALITY AND SELF HARM
3.1 SUBJECTIVE EMOTIONAL DISTURBANCE	7.4 MOOD SWINGS/LABILITY
3.2 OBSERVED BLUNTED AFFECT	7.5 ANXIETY
3.3 OBSERVED INAPPROPRIATE AFFECT	7.6 OCD SYMPTOMS
4: NEGATIVE SYMPTOMS	7.7 DISSOCIATIVE SYMPTOMS
4.1 ALOGIA	7.8 IMPAIRED TOLERANCE TO NORMAL STRESS
4.2 AVOLITION/APATHY	
4.3 ANHEDONIA	
5: BEHAVIOURAL CHANGE	
5.1 SOCIAL ISOLATION	
5.2 IMPAIRED ROLE FUNCTION	
5.3 DISORGANISING/ODD/STIGMATISING BEHAVIOUR	
5.4 AGGRESSION/DANGEROUS BEHAVIOUR	

UHR status was also assessed in terms of 'basic' symptoms, using a shortened version of the Schizophrenia Proneness Instrument for Adults (SPI-A; Schultze-Lutter et al., 2007a) comprised of the nine items found to be most predictive of later schizophrenia (Schultze-Lutter, 2001). This cluster of nine basic symptoms (inability to divide attention, thought interference, though pressure, thought blockages, disturbance of receptive speech, disturbance of expressive speech, unstable ideas of reference, disturbances of abstract thinking, and captivation of attention by details of the visual field) has been previously described as the high risk cognitive disturbances criterion (Klosterkötter et al., 2005; Schultze-Lutter et al., 2007b) but shall hereon be referred to as the SPIA-9. The SPIA-9 is rated on a Likert scale based, in most circumstances, on frequency (0-6), with additional options (7-9) for suspected, unknown frequency and trait status. For further detail please see Appendix B (p.241). Participants were regarded as meeting UHR criteria if they scored sufficiently highly on

either the CAARMS or the SPI-A; it was not necessary for participants to meet criteria for both (although it was expected that some would).

As in the OASIS screening interview, the SPIA-9 was integrated into the first section of the CAARMS. In this interview the items used to rate the SPIA-9 are incorporated into the questions for the first four subscales of the CAARMS (Appendix B). In this way the two assessments can be rated from the same interview. The reasons for combining the two UHR measures in this way are twofold; firstly, this would again remain consistent with the practice within the OASIS clinical service, and secondly this provided the least disjointed experience for those undergoing the interview and thus was the most efficient use of the limited time available.

5.1.1 Timing of symptoms

The CAARMS is designed to be used in a clinical context where patients may be interviewed over time at various intervals in order to assess any worsening in condition or any other changes in symptoms. Upon screening a help-seeking patient, the CAARMS interview is typically conducted with reference to the preceding year, after which it can be repeated as frequently as every month. It is not known exactly what causes individuals to seek help in the first place and indeed this is likely to vary widely across individuals. However, it seems likely that patients approaching or being referred to the OASIS service are likely to have begun experiencing symptoms or associated social, emotional and vocational problems in the few months beforehand. In the present study, the sample differed in that it was not ascertained from help-seeking people referred to a clinical service, but randomly sampled from the general population. With this in mind the decision was taken to use the CAARMS interview with particular reference to whether symptoms were present in the previous three months, as opposed to the twelve months when the CAARMS is used in clinical high risk services. This was intended to give an indication of which individuals might be most likely to seek help from OASIS at that time, thus taking a more conservative approach to identifying UHR individuals. Since previous studies have also highlighted the potential seriousness of persistent psychotic experiences, while indicating that transitory experiences are far more common and far less problematic (Dominguez et al., 2011; Kaymaz et al., 2012; Wigman et al., 2011), it seemed appropriate not to include individuals who may have had transient experiences in the past year but which had not occurred in recent months. This approach can be considered to provide a snapshot of what the prevalence of symptoms and experiences might be in the general population at a given time.

Additional information about potentially psychotic symptoms over longer time periods was collected using the PSQ (past twelve months) and the CAPE (lifetime). Both of these are described below.

5.1.2 Attenuated psychotic symptoms

Those experiencing attenuated psychotic symptoms make up the majority of individuals accessing ultra high risk services (e.g. Fusar-Poli et al., 2013; Raballo et al., 2011). This refers to the presence of positive psychotic symptoms but to a degree that does not meet the threshold for a first episode of psychosis. The PACE criteria split this further into two subgroups to distinguish symptoms that are either of sub-threshold intensity or of sub-threshold frequency (see CAARMS intake criteria: Appendix B). As discussed above, the PACE criteria require symptoms to be present within the past twelve months, whereas in this study this was revised to the last three months.

The recent version of the PACE criteria published by Yung et al. (2006b) includes a revision that requires that attenuated symptoms should not only be present, but occur within the context of a recent decline in social and occupational functioning or persistent low functioning over the previous 12 months. This decline is defined as a reduction of 30% or greater on the Social and Occupational Functioning Assessment Scale (SOFAS; included in DSM-IV), while persistent low functioning refers to an absolute score of 50 or lower on the same scale, present for at least 12 months. This recent revision was not applied in the present study. There are a number of reasons for this decision. Firstly, the functioning requirement did not appear in the original version of the PACE criteria (e.g. Yung et al., 2005). In clinical practice this criterion is often not employed, as it would result in the turning away of help-seeking people who have distressing symptoms and might still benefit from clinical care. Furthermore, in practice it is sometimes difficult to accurately assess the degree to which function has declined on the basis of patchy and retrospective information. In the present study, it was decided that since participants were only to be interviewed once, functional decline could not be measured sufficiently accurately to be included as a criterion.

5.1.3 Brief limited intermittent psychotic symptoms (BLIPS)

The BLIPS group defines individuals as UHR owing to a recent history of frank psychotic symptoms, which spontaneously remit within one week without the use of antipsychotic medication (again, see CAARMS intake criteria: Appendix B). Symptoms must be present within the last year and are not restricted to a single episode, provided no episode exceeds one week in duration. Any subjects whose symptoms do not remit within one week, or who receive anti-

psychotic medication, are classified as having made a transition to psychosis. As with the above, the additional functional deficit was not included in the present study.

5.1.4 Trait and state vulnerability

Criteria for the vulnerability group required the presence of a trait risk factor (either a genetic risk of psychosis or a schizotypal personality disorder) along with either a recent decline in function or a recent history of chronically poor functioning.

Genetic risk

Individuals were classified as being at genetic risk if a first degree relative had a history of any psychotic disorder. This was assessed using the Family Interview for Genetic Studies (FIGS; NIMH Genetics Initiative, 1992) in which a series of screening questions are used to elicit information about possible mental health problems among participants' first degree relatives, namely their parents, siblings and children. Positive responses to any of these are followed up with more specific questions about the duration and severity of symptoms and the receipt and type of treatment for each potentially affected relative. From this the presence of a first degree relative with a history of psychotic disorder could be derived. When used with psychosis patients, the FIGS is often conducted with a family member in order to increase the reliability of information. However, since present study population was non-clinical, this was not seen as a concern and interviews were conducted with the participant.

Schizotypal personality disorder

Schizotypal personality disorder is described by the DSM-IV-TR as:

> *"A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships as well as by cognitive or perceptual distortions and eccentricities of behavior, beginning by early adulthood and present in a variety of contexts" (American Psychiatric Association, 2000)*

This was screened using the schizotypal personality section of the Structured Clinical Interview for DSM-IV – Axis II disorders (SCID II; First et al., 1997). This semi-structured clinical interview is based on the DSM-IV-TR criteria and elicited information about nine particular traits which were rated on their presence and severity (see Appendix B, p.233). Within this interview, items 4-7 are rated from the interviewer's observation and on the basis of information elicited elsewhere in the appointment. At least five of the nine items must be present at threshold level to be regarded as exhibiting a schizotypal personality disorder.

Assessment of functioning

Functioning was measured using a dual version of the Global Assessment of Functioning (GAF; American Psychiatric Association, 2000, p. 34) similar to that defined by Goldman, Skodol and Lave (1992). This produces two scales, one measuring psychological functioning and global symptom level (GAF-S) and the other measuring social, interpersonal and occupational functioning (GAF-F). Both scales are rated in the same way as the standard GAF. Ratings were based on information elicited from the subject throughout the interview and from additional questioning wherever anything was unclear. All GAF scores relate to functioning within the previous month.

Ratings were completed by a number of different researchers within CAPsy, creating the potential for inter-rater reliability issues. With this in mind, raters were required to complete online training and reliability exams on the EU-GEI website periodically throughout the data collection process. This was regarded as sufficient since satisfactory levels of agreement can be achieved with the GAF after only a single training session (Jones et al., 1995). Moreover, researchers were encouraged to refer to a revised form of the modified GAF as adapted by the Florida DCF Functional Assessment Workgroup (available online: http://www.dcf.state.fl.us/programs/samh/mentalhealth/mgaf.pdf), which provides specific guidance on how to rate within each ten-point range. This makes for less subjective and more reliable ratings (Hall, 1995).

The PACE criteria define a decline in functioning as being a 30% drop in SOFAS, and low functioning as a score of less than 50, which must be present for the past 12 months to be considered chronic. As discussed above, functional decline could not be measured accurately in the present study; however, an indication of functional decline was required in order to define the genetic risk and decline group. Consequently participants were asked to describe and reflect on any recent changes in occupational or relationship status, general stress levels and psychological wellbeing and to rate their change in functioning over the previous two years on an ordinal scale: marked decline, mild decline, no change, or improvement. Only those reporting a marked decline were considered to meet PACE criteria for this group.

5.1.5 Basic symptoms

Participants were assessed for basic symptoms using the SPIA-9. They were questioned as part of a semi-structured interview about experiences they may have had (e.g. “Do you sometimes have the feeling that you were not able to control your thoughts anymore? That your thoughts would just run wild?”). Responses were then compared to the detailed descriptions of basic symptoms provided in the SPI-A rating manual (Schultze-Lutter et al.,

2007a) to assess whether the experiences reported were of sufficient intensity to be considered basic symptoms. Symptoms that matched the descriptions were then rated for their presence on an ordinal scale of 0-6, primarily in terms of frequency, as described above.

To meet the criteria for UHR status participants must receive a rating of 3 or above for two or more of the nine basic symptoms. These must also be present within the past three months. Ratings of 7, 8 and 9 indicated a lack of certainty about the reported experience being a genuine basic symptom (rather than a trait for instance) and were therefore treated as missing.

5.1.6 Negative symptoms

In light of recent studies about the importance of negative symptoms in the experience and progression of the UHR state (Demjaha et al., 2010; Dominguez et al., 2010; Fusar-Poli and Borgwardt, 2007), the OASIS service recently expanded its intake criteria to include individuals who are experiencing sub-threshold negative symptoms rather than just positive or basic symptoms. Negative symptoms are assessed on the basis of five subscales of the CAARMS: 3.1 Subjective Emotional Disturbance, 3.2 Observed Emotional Disturbance, 4.1 Alogia, 4.2 Avolition/apathy and 4.3 Anhedonia. Rating criteria mirror those of the attenuated psychosis group in that negative symptoms may be of either sub-threshold intensity or sub-threshold frequency.

The sub-threshold intensity subgroup requires that a CAARMS global severity rating scale score of 3-4 on the Alogia subscale, 3-4 on Avolition/Apathy, 3-5 on Anhedonia, 3-5 on Subjective Emotional Disturbance, and/or 3-4 on Observed Emotional Disturbance, along with a rating of 3-6 on the corresponding frequency scale. To meet these criteria symptoms must be present for at least one week. Alternatively, the sub-threshold frequency subgroup is defined by a global severity rating or 5-6 on the Alogia subscale, 5-6 on Avolition/Apathy, 6 on Anhedonia, 6 on Subjective Emotional Disturbance, and/or 5-6 on Observed Emotional Disturbance. In addition they must receive a rating of 3-4 on the corresponding frequency score. For both subgroups the symptoms must be present within the last twelve months.

5.1.7 Distress

The CAARMS includes a subjective rating of distress for each of its first four subscales (positive symptoms). Here, participants are asked how distressing each experience or symptom is (on a scale 0-100). Distress is not one of the PACE criteria, but the presence of distress is taken into account within the global severity rating for each symptom subscale. In addition it is used clinically to indicate which symptom (or symptoms) may be most troubling

for the patient and thus ought to be the primary focus for treatment. Within the present study this distress scale was replicated for the remaining subscales throughout the CAARMS and also for basic symptoms rated on the SPIA-9. It was decided that this information could be informative when examining the primary hypotheses concerning help-seeking. Subjective distress ratings were collected for every symptom reported. For each participant, mean distress scores were calculated for positive symptoms, basic symptoms, negative symptoms and general psychopathology. In addition, the score for the most distressing symptom within each of the four above types was recorded, to indicate the maximum level of subjective distress experienced in relation to each.

5.1.8 Exclusion criteria: the psychosis threshold

As part of identifying UHR individuals, the CAARMS is also designed to identify when individuals have made a transition to frank psychosis. The psychosis threshold criteria are defined in the CAARMS intake criteria (Appendix B). The OASIS service has also defined a psychotic threshold based on negative symptoms. To meet this inclusion criterion, subjects must receive a global severity score of 6 on at least two of the following subscales of the CAARMS: Alogia, Avolition/Apathy, Anhedonia, Subjective Emotional Disturbance, and Observed Emotional Disturbance. In addition, the negative symptom in question must receive a frequency rating of greater than or equal to 5. For both groups, symptoms must have been present for more than one week. Finally, overall functioning must be low, with a GAF or SOFAS score of less than 40.

5.1.9 Reliability

The CAARMS is a clinical tool designed to be used by trained clinicians and researchers on a help-seeking population that is referred to a clinical service. In this study I used the CAARMS on a generally non-help-seeking non-clinical sample.

As a semi-structured interview with thorough and specific rating criteria, the CAARMS is designed to be relatively unambiguous and easy to use, and indeed the CAARMS shows good to excellent inter-rater reliability (Yung et al., 2005). Because all the CAARMS assessments required for the present study were conducted by one rater (me), inter-rater variation within the sample was not a concern. However, it was important that I was sufficiently trained in the use of the CAARMS, and to test whether these ratings corresponded with those that would have been made by independent raters of the same subjects.

I attended a CAARMS training workshop at the OASIS service, led by Steven Badger, who has been the OASIS team leader since the service began in 2001. Training was provided to a

small cohort of clinicians and other researchers involved with the European Network of Schizophrenia Networks for the Study of Gene-Environment Interactions (EU-GEI). This involved initially going through the CAARMS interview section by section to familiarise ourselves with the tool. Following this we were trained to use to CAARMS through a combination of recorded interviews and written vignettes. These training materials were designed and provided by the same clinicians at the Melbourne PACE clinic who designed the CAARMS (see Nelson et al., 2008). This is the standard training received by all researchers who will be using the CAARMS. I also attended a refresher CAARMS training session during my data collection the following year, again at the OASIS service.

I undertook additional training via the EUGEI project website, which included practice vignettes and a video exam to check CAARMS ratings against a central gold standard. After the training exam, test videos were made available in May 2010, October 2011 and May 2013 in order to ensure that inter-rater reliability remained at an adequate level between researchers across Europe throughout the data collection process. The exams themselves were provided by a research group from the Netherlands, using the first four subscales of the CAARMS. Although the interviews were in Dutch with English subtitles, 83% agreement was achieved across all ratings. More importantly, the four exams were completed with a 100% success rate with regards to the diagnostic outcome.

In practice, initial assessments using the CAARMS were conducted in pairs so that ratings could be discussed and a consensus reached. Joint-ratings were provided by different researchers in order to account for bias and to improve reliability across all raters. Throughout data collection, home visits were attended in pairs for safety reasons and on these occasions the opportunity was often taken to again provide joint ratings.

5.2 Other clinical measures

The present study also aimed to explore the presence of other subclinical symptoms and psychotic experiences that may be present within the population, as well as the UHR state. At a community level this would help to build a clearer picture of the prevalence of subclinical psychotic experiences in the catchment area and how this compares with other geographical areas where these symptoms have been studied. The study also aimed to examine non-psychotic experiences and symptoms, such as anxiety and depression, and how these are related to psychotic experiences and with help-seeking behaviours. It is important to be aware that many people approach the OASIS service as a result of social, emotional and vocational problems rather than positive symptoms. Previous research has indicated that help-seeking in the early stages of psychosis may often be driven by affective symptoms or occupational

decline (Addington et al., 2002). It was therefore important to gather information about this wider clinical profile in order to better understand these behaviours.

5.2.1 Subclinical psychotic experiences

The Psychosis Screening Questionnaire (PSQ; Bebbington and Nayani, 1995) was used to elicit information on psychotic experiences, administered in the same way as described in Chapter 3. Again, items relating to hypomania were discarded and comparisons were primarily made between those who endorsed one or more key question in the remaining four domains on the PSQ with those who did not. The PSQ was also the only psychosis measure to be included at both time points. Therefore within the nested longitudinal sample the PSQ could be used to examine the stability of psychotic experiences over time as well as their value in predicting UHR status and other psychopathology at time 2.

Information on lifetime psychotic experiences was elicited using the Community Assessment of Psychotic Experiences (CAPE; Stefanis et al., 2002). The CAPE is a 42-item self-report questionnaire which can be seen in full at http://cape42.homestead.com/index.html. For each item, participants are asked firstly how often they have had a certain experience throughout their lifetime and secondly how distressed they were by it. In addition to an overall score, the CAPE has three dimensions: positive (e.g. “Do you ever think that people can communicate telepathically?”), negative (e.g. “Do you ever feel that you have no interest to be with other people?”) and depressive (e.g. “Do you ever cry about nothing”). Weighted scores for each dimension are created by summing the scores for each contributing item and dividing by the number of contributing items completed by the subject. Overall and dimensional distress scores can be calculated in exactly the same way using the distress scores rather than frequency. The three dimensions of the CAPE are shown in full in Table 6.3 (p.87).

The CAPE has been shown to be stable, reliable and valid for use in general population samples (Konings et al., 2006) and has recently been shown to be a useful screening tool for the UHR state (Mossaheb et al., 2012). For these reasons it may be another useful way to classify individuals; it may be able to identify individuals who report psychotic symptoms but fall slightly short of meeting the UHR criteria, particularly within the three month time frame adopted by the present study.

5.2.2 Affective measures

Symptoms of depression and anxiety were measured using Hamilton’s Depression scale (HAM-D; Hamilton, 1960) and Hamilton’s Anxiety scale (HAM-A; Hamilton, 1959). These are both semi-structured interviews and relate to symptoms present within the preceding seven

days. The two measures are conducted and scored in exactly the same way. Participants were asked an initial question for each item, which aimed to elicit the required information about the severity and frequency of a given symptom, for example “How has your appetite been this past week?” Suggested follow up questions are then provided to increase certainty in the scoring, such as “Have other people had to urge you to eat?” On the basis of this questioning, the interviewer is then required to rate each item according to the descriptions given for each interval. Scores ranged between 0-2 and 0-4. In addition, three items within the HAM-D are based on the interviewer’s observation (insight, retardation and agitation). Total scores for HAM-D and HAM-A could then be produced by summing the item scores within the scale.

5.2.3 Wider clinical presentation: CAARMS

As mentioned previously, participants were interviewed using the full CAARMS. In addition to the four positive symptoms subscales, the full CAARMS includes six sections which assess negative and cognitive symptoms; changes in emotion, behaviour and functioning; physical changes and general psychopathology (see Table 5.1). Severity, frequency and distress scores were recorded for each of the subscales. These could be examined in isolation or in terms of an overall score for the section. Using the process described by Morrison et al. (2012) for the positive symptoms section, section sub-scores were calculated by summing the products of the global rating and frequency scores within each subscale. The maximum score varied according to the number of subscales within a section so, for example, the theoretical maximum section score for positive symptoms was 144 (6x6 + 6x6 + 6x6 + 6x6 = 144). Distress was taken as the mean distress for all symptoms reported within a section.

5.3 Non clinical measures

5.3.1 Sociodemographic information

All participants completed an amended version of the Medical Research Council’s Sociodemographic Schedule (Mallet, 1997), which provides detailed information about age, gender, self-ascribed ethnicity, individual and parental place of birth, level of education, living circumstances, occupation and socio-economic status, relationship status, and religion. It was designed to be particularly useful in studies that include ethnic minorities. Elements relevant to this thesis are described here in more detail.

Participants were asked to indicate their ethnic origin based on 18 categories used by the UK Office of National Statistics (ONS) census in 2011. For the analysis, the smallest categories were collapsed into an ‘Other’ group (Mixed groups, Black Other, and Other), a ‘White Other’ group (White Irish, White gypsy, and White Other), and an ‘Asian (all)’ group (Indian, Pakistani,

Bangladeshi, Chinese, and Other Asian). This left six ethnicity groups: White British, White Other, Black African, Black Caribbean, Asian (all), and Other.

Participants' migrant status was derived from their place of birth. For first generation migrants a continuous variable was also derived to represent 'years spent in the UK' at the time of interview. An extensive literature has linked migrancy and ethnic density of an area to experiences and symptoms all along the psychosis continuum. It was posited that unfamiliarity with the culture may be partly involved in explaining this association; therefore years in the UK may be important to take into account.

Information was also collected about the participant's first language. Specifically for this thesis, a binary variable was derived to indicate those who reported a first language other than English. Participants who were not native English speakers were also asked to rate their fluency in the English language on a scale from 1 to 10 (1 = not fluent at all, 10 = very fluent). Native English speakers were automatically given a 10. This was used in the analysis to control for potential misunderstandings in questioning and the validity of neurocognitive assessments.

Participants were asked to select the highest level of education they obtained from a six-point ordinal scale. These categories were recoded into three variables: 'School' (those who received compulsory education and left with or without qualifications), 'Further Education' (those who completed A-levels or equivalent or vocational training), and 'Higher Education' (those who completed an undergraduate or post-graduate degree).

Data on employment status was obtained in relation to three different time points during the interview: present status, status exactly one year prior to the interview, and status five years prior to the interview. If the participant was younger than 17 years of age during the time period in question, their answer was coded as 'not applicable'. For the analysis, employment status groups were collapsed into: 'unemployed', 'employed' (part time, full time, self-employed), and 'economically inactive' (including student, retired, house person, disabled, and those aged under 17). Participants were also asked about details of their occupation, such as their job title and whether they were directly responsible for managing others in that role. This information was used to assign social class using the Registrar General's system of classification.

Questions relating to living status (including how many others lived with them) and relationship status were used to derive indicators of social isolation. Participants were asked about these in relation to the same three time points as outlined above, provided they were at least 17 years old at the time. A binary variable for living isolation was formed to identify participants who currently lived "alone" or "alone, with children" as opposed to living with friends, family or a partner. The original relationship status variable was also collapsed into

two groups: participants who defined themselves currently as 'single' (single, divorced/separated, widowed) and those who identified as currently 'in a relationship' (married/living with someone, in a steady relationship). A variable was also created to indicate a recent loss of relationship, which might be a potential source of stress. This was a binary variable created by comparing current relationship status with that of one year prior to interview and identifying individuals who had changed from being 'in a relationship' to 'single'. This might be thought of as acute isolation. In contrast, a binary variable for chronic isolation was created which identified individuals who reported themselves to be 'single' at all three time points.

Participants were asked which of five categories best described their religious affiliation (none, Christian, Jewish, Muslim, or other). They were also asked to indicate the frequency of their attendance at religious services on four-point ordinal scale (never, once or twice per year, monthly, or weekly). This provided an index for religious commitment (treated as a potential proxy for the strength of religious belief) and could be analysed independently of religious affiliation.

5.3.2 Help-seeking and service use

Information on help-seeking and use of health services in the past year using was collected using questions from the US National Comorbidity Survey. Specifically, help-seeking for psychological issues was assessed using the question: "In the PAST 12 MONTHS, have you spoken to anyone (professional or non-professional), either in person or by telephone, about problems with your emotions or nerves or your use of alcohol or drugs?" Positive responses to this were followed up by asking the participant to select who it was that they spoke to from a list (1. GP or family doctor, 2. Psychological therapist/counsellor, 3. Mental health specialist, 4. Friends, 5. Family Member, 6. Spiritual/Religious leader, or 7. Other). Help-seeking intention among those who had not spoken to anyone was assessed with the question: "Was there ever a time during the PAST 12 MONTHS when you felt that you might need to see a professional because of your emotions or nerves or your use of drugs or alcohol?" Reasons for non-help-seeking were explored among those who reported this intention. Contact with counselling services was measured with the question: "Have you ever been seen by a counsellor, psychotherapist, clinical psychologist or other therapist for a 'talking therapy'?" This included counselling related to bereavement and/or problems with substance use.

Attitudes towards health service use were measured with four questions. Three questions related to hypothetical scenarios such as "If you had a serious emotional problem, would you go for professional help?" Responses were given on a four-point Likert scale (Definitely,

Probably, Probably not, Definitely not). Finally participants were asked what percentage of persons they believe benefit from professional treatment for emotional problems (of all those who receive it). This was recorded to the nearest 10%.

The questionnaire used to elicit data on help-seeking and service use provides a useful and informative overview; however, it is limited by its lack of specificity. As discussed in Chapter 3 it is not clear exactly what had led participants to seek help. To combat this, questions were built into the CAARMS and SPIA-9 interviews so that each symptom reported was also assessed in terms of help-seeking (within the last 3 months). This took place at the time that the symptom was discussed so it could be clear what the help-seeking was in response to. Actual help-seeking was assessed by asking participants if they had spoken to anyone (professional or non-professional) about the symptom in question and, if so, who that was. Responses were coded against the list described above, with the exception that "partner" was included as an additional option. Participants who had not seen a health professional were also asked whether they had thought that they should see one because of the experience. This was again to assess help-seeking intention.

This information was included so that it could be seen exactly what experiences and symptoms (psychotic or otherwise) are the ones that lead individuals to seek help and from whom.

5.3.3 Need for care

Need for care was assessed using the Camberwell Assessment of Need Short Appraisal Scale (CANSAS; Slade et al., 1999). Modified from the Camberwell Assessment of Need (Phelan et al., 1995), the CANSAS is quick to administer and assesses needs in 22 health and social domains. Each domain is rated as either an unmet need (current serious problem, regardless of any help given), met need (no/moderate problem because of help given), or no need. Following the recommendations of the authors (http://www.researchintorecovery.com/adultcanresearch), attention was paid to the total number of (met or unmet) needs and the total number of unmet needs for each individual. Both scores ranged from 0 to 22, with higher scores indicating greater need for care.

5.3.4 Family history of mental health problems

The FIGS was administered as described above. Screening questionnaires were used to obtain information about possible mental health problems suffered by relatives of the participant (specifically depression, mania, psychosis, obsessive compulsive disorder, and autism). Positive answers led to follow up questions, which elicited details of symptom level

and of treatment. As well as being linked to a family history of psychotic disorder, subclinical psychotic symptoms have been associated with a family history of depression (Zammit et al., 2008). In order to investigate this relationship in the present sample, variables were derived from FIGS to indicate a family history of any mental health problem, and a family history of any non-psychotic mental health problem.

5.3.5 Childhood trauma

Childhood trauma was assessed using the short form Childhood Trauma Questionnaire (CTQ; Bernstein et al., 2003). This is a 25-item questionnaire which requires participants to indicate how well each statement matched their experiences before age 17, using a five point likert scale. Importantly, participants are asked to complete this unobserved by the interviewer and to place the completed questionnaire in a sealed envelope, thereby reducing the impact of social desirability and making it easier for participants to convey traumatic experiences without having to speak about them in detail. The overall mean score of these 25 items was used to create a continuous variable for childhood trauma, akin to the total score used in other UHR studies (Şahin et al., 2013; Thompson et al., 2014).

5.3.6 Neurocognitive assessment

Participants' Full Scale Intelligence Quotient (FSIQ) was used as an index of cognitive impairment, assessed using a shortened version of the Wechsler Adult Intelligence Scale III (WAIS-III), as proposed by Velthorst and colleagues (2013). This has been shown to produce reliable estimates of FSIQ in schizophrenia patients, their siblings and healthy controls (Velthorst et al., 2013) and can be administered in just fifteen minutes. The contents of this assessment, along with scoring instructions, are included in Appendix B (p.242). Because of the length of the overall interview and the secondary nature of IQ within the hypotheses of both the EU-GEI and this thesis, this shortened version was deemed both adequate and the most efficient use of limited time.

5.3.7 Cannabis use

Participants were assessed for their recent and lifetime use of cannabis using items from the Cannabis Experience Questionnaire (Barkus et al., 2006).

CHAPTER 6 METHODS (3): DATA PROCEDURES, PREPARATION AND ANALYSIS

6.1 Data storage and protection

In accordance with the data protection act the data collected were physically stored in locked cabinets in a locked office, accessed only by a small number of researchers. Assessment folders did not contain any personally identifiable information and were identified only by a unique identification number (subject ID). Anything containing identifiable information, such as consent forms and payment receipts, was stored separately from assessment data, again in locked storage. A case-log was stored digitally as an encrypted Excel file and was used to match subjects to their subject ID numbers and to keep a record of appointments and contacts.

6.2 Data entry and reliability checking

Errors in data entry can create problems for the validity of a study. To combat this, data entry forms were created using Microsoft Access 2010. This prevented entry errors by ensuring the integrity of subject IDs (i.e. that they were unique and matched across measures), enforcing skip logic for complex questionnaires, highlighting any internal inconsistencies in assessments and preventing variables from being left blank. In addition to this, data for eight key measures were double entered for 10% of the sample, selected at random. Agreement figures ranged from 98% to 100%, with a mean agreement of 99.6% across scales and 99.8% across data points. All errors identified were checked and in each case the entry error had occurred during re-entry. Taken together, these encourage a high level of confidence that trends found in the data will not be the result of entry error.

6.3 Data preparation

Data were imported into Stata 11.2 (StataCorp, 2009) and then prepared for analysis.

6.3.1 Data screening

Data were screened according to the guidelines suggested by Tabachnick & Fidell (2013). Data were inspected for errors, such as date of birth not corresponding with age; for out-of-range values, such as assessment scores exceeding the maximum for that scale; and for plausible means and standard deviations. Univariate outliers were identified and examined to ensure that these did not represent deviations from the study population of interest. Since the aim of the study was to obtain a representative general population sample, a large degree of variation was expected and no evidence was found to support the removal of any individuals

from the study. Data were therefore kept, providing that scores appeared to be valid. Where reason was found to question the validity of a score, for example an extremely low IQ score in someone who had had language difficulties during the assessment, the data point was recoded as 'missing'.

Table 6.1 Missing data across primary variables used in the thesis (N= 208)

	Measure / Variable	Missing	
		n	(%)
i.	Wechsler Adult Intelligence Scale – shortened (WAIS)	15	(7.2%)
ii.	Cannabis Experience Questionnaire (CEQ)	9	(4.3%)
iii.	GAF-S	4	(1.9%)
iv.	GAF-F	4	(1.9%)
v.	Community Assessment of Psychotic Experiences (CAPE)	3	(1.4%)
vi.	CAARMS – General psychopathology	2	(1.0%)
vii.	CAARMS – Negative symptoms	1	(0.5%)
viii.	Living arrangements	1	(0.5%)
ix.	Hamilton's Depression scale (HAM-D)	1	(0.5%)
x.	Hamilton's Anxiety scale (HAM-A)	1	(0.5%)
xi.	Childhood Trauma Questionnaire (CTQ)	1	(0.5%)
	Age	0	(0.0%)
	Sex	0	(0.0%)
	Ethnicity	0	(0.0%)
	Education level	0	(0.0%)
	Employment status	0	(0.0%)
	Relationship status	0	(0.0%)
	Migrant status	0	(0.0%)
	SPIA-9	0	(0.0%)
	Psychosis Screening Questionnaire	0	(0.0%)
	Family Interview for Genetic Studies (FIGS)	0	(0.0%)
	CAARMS – Positive symptoms	0	(0.0%)
	Help-seeking (healthcare and service use)	0	(0.0%)

6.3.2 Missing data

The amount of missing data was evaluated and patterns were investigated using guides and downloaded Stata commands from the UCLA Statistics Consulting group (available online

at: http://statistics.ats.ucla.edu/stat/stata/faq/nummiss_stata.htm, accessed 05/06/14). Frequencies of missing data for the main variables used in the thesis are shown in Table 6.1. There were various reasons that data might be missing. The WAIS and the CEQ were considered to be lower priority assessments and were included towards the end of the final appointment. On occasion participants were unable to complete a third appointment for the study or opted to cut short the appointment because of time and these assessments were therefore missed. In addition, administration of the WAIS required a suitable distraction-free setting which was sometimes not possible during home visits. GAF-S and GAF-F scored were assessed from the same interview, so the same four individuals have data missing for both GAF scales. The CAARMS was completed for every participant, although there were data missing for symptom frequency on three occasions.

Patterns of missing data were explored and are displayed in Table 6.2. This exploration revealed a great number of different patterns of missing data, each present in very few individuals. This is consistent with data being missing at random. Of the 208 participants, 25 (12%) had missing data for at least one variable. Among those with missing data, more than two thirds were missing only one variable (n = 17, 68%) and only one individual was missing more than three variables. This individual was interviewed very early in the study, when some measures had yet to be included and before research interviewers had learned to administer assessments as efficiently. They also did not complete a final appointment. Nevertheless, the key measures for this thesis were completed sufficiently to be included in the study sample.

Finally, variables with 5% missing data or more were examined in more detail to assess any systematic trends. This analysis was therefore carried out only for the WAIS. A series of chi-squared tests was performed to examine whether six basic demographic variables were associated with the WAIS being missing. Since Type II errors were more of a concern than Type I errors in this analysis, no corrections were made for multiple testing. No evidence was found for an association with age, sex, ethnicity, migration status, or level of education. However, there was a statistically significant association between missing WAIS and current unemployment: $\chi^2(1) = 6.42$, $p = .011$. Although this could be potentially problematic, the magnitude of the effect was small [$r = .176$]. Moreover, IQ was mainly for use in secondary analyses and was not one of the primary outcome variables of the present study. Nevertheless, any conclusions relating to the WAIS need to be made with caution.

Table 6.2 Pattern of missing data

Variables†											Missing values	Frequency
i.	ii.	iii.	iv.	v.	vi.	vii	viii.	ix.	x.	xi.		
+	+	+	+	+	+	+	+	+	+	+	0	183
.	+	+	+	+	+	+	+	+	+	+	1	10
.	.	+	+	+	+	+	+	+	+	+	2	3
+	+	+	+	+	.	+	+	+	+	+	1	2
+	+	+	+	.	+	+	+	+	+	+	1	2
+	.	+	+	+	+	+	+	+	+	+	1	2
+	.	.	.	+	+	+	+	+	+	+	3	2
+	+	+	+	+	+	.	+	+	+	+	1	1
+	+	.	.	+	+	+	+	+	+	+	2	1
.	.	+	+	+	+	+	.	+	+	+	3	1
.	.	.	.	.	+	+	+	.	.	.	8	1

Note: Shaded cells indicate missing data

† see Table 6.1 for list of variables

6.3.3 Scales and reliability

There were a number of measures for which the raw interview data was converted into individual subscales. Data screening took place for both raw data and the derived variables. Internal reliability of the resulting variables was assessed using Cronbach's alpha, a widely used objective measure of reliability. While Cronbach's alpha is not sufficient to confirm the unidimensionality of a scale, internal consistency is a necessary part of this and so an acceptable[1] alpha score is consistent with unidimensionality (Tavakol and Dennick, 2011). It was deemed appropriate in this case since dimensional scales were determined a priori and have all been used elsewhere.

Dimensional scores for the CAPE were derived by calculating the mean score for items within each subscale. To account for incomplete data, means were only calculated if 70% of items were present (14/20 items on the positive subscale, 10/14 items on the negative subscale and 6/8 items on the depressive subscale), in accordance with the EUGEI protocol.

[1] There is debate over what level of alpha is considered to be acceptable. However, suggestions for the minimum cut-off appear to be mostly between 0.7 and 0.9 (Bland and Altman, 1997; Field, 2013), although scores higher than 0.9 may indicate item redundancy (Tavakol and Dennick, 2011).

Cronbach's alpha was calculated for each of the subscales, showing good internal consistency throughout ($\alpha = 0.80 – 0.83$). The resulting dimensions and alpha scores are shown in Table 6.3. Intercorrelation between the three subscales was moderate to strong (see Table 6.4) but did not show evidence of co-linearity, supporting the distinction between these scales.

Table 6.3 Dimensions and internal consistency of the CAPE

Dimension	Cronbach's alpha
Positive Dimension (20 items)	0.81
2. Do you ever feel as if people seem to drop hints about you or say things with a double meaning?	
5. Do you ever feel as if things in magazines or on TV were written especially for you?	
6. Do you ever feel as if some people are not what they seem to be?	
7. Do you ever feel as if you are being persecuted in some way?	
10. Do you ever feel as if there is a conspiracy against you?	
11. Do you ever feel as if you are destined to be someone very important?	
13. Do you ever feel that you are a very special or unusual person?	
15. Do you ever think that people can communicate telepathically?	
17. Do you ever feel as if electrical devices such as computers can influence the way you think?	
20. Do you belief in the power of witchcraft, voodoo or the occult?	
22. Do you ever feel that people look at you oddly because of your appearance?	
24. Do you ever feel as if the thoughts in your head are being taken away from you?	
26. Do you ever feel as if the thoughts in your head are not your own?	
28. Have your thoughts ever been so vivid that you were worried other people would hear them?	
30. Do you ever hear your own thoughts being echoed back to you?	
31. Do you ever feel as if you are under the control of some force or power other than yourself?	
33. Do you ever hear voices when you are alone?	
34. Do you ever hear voices talking to each other when you are alone?	
41. Do you ever feel as if a double has taken the place of a family member, friend or acquaintance?	
42. Do you ever see objects, people or animals that other people cannot see?	

Dimension		Cronbach's alpha
Negative Dimension	(14 items)	0.83
	3. Do you ever feel that you are not a very animated person?	
	4. Do you ever feel that you are not much of a talker when you are conversing with other people?	
	8. Do you ever feel that you experience few or no emotions at important events?	
	16. Do you ever feel that you have no interest to be with other people?	
	18. Do you ever feel that you are lacking in motivation to do things?	
	21. Do you ever feel that you are lacking in energy?	
	23. Do you ever feel that your mind is empty?	
	25. Do you ever feel that you are spending all your days doing nothing?	
	27. Do you ever feel that your feelings are lacking in intensity?	
	29. Do you ever feel that you are lacking in spontaneity?	
	32. Do you ever feel that your emotions are blunted?	
	35. Do you ever feel that you are neglecting your appearance or personal hygiene?	
	36. Do you ever feel that you can never get things done?	
	37. Do you ever feel that you have only few hobbies or interests?	
Depressive Dimension	(8 items)	0.80
	1. Do you ever feel sad?	
	9. Do you ever feel pessimistic about everything?	
	12. Do you ever feel as if there is no future for you?	
	14. Do you ever feel as if you do not want to live anymore?	
	19. Do you ever cry about nothing?	
	38. Do you ever feel guilty?	
	39. Do you ever feel like a failure?	
	40. Do you ever feel tense?	

Table 6.4 Intercorrelation of derived CAPE dimensions

Dimensions	**Positive**	**Negative**	**Depressive**
Positive	--		
Negative	0.43	--	
Depressive	0.32	0.63	--

The CTQ has been used elsewhere as independent dimensional scales corresponding with different kinds of childhood trauma. However, this was not the focus of the present study and as such just the overall score was computed in relation to any kind of childhood trauma (as in Thompson et al., 2014). This scale comprised 25 items and showed very strong internal consistency (α = .93), which could indicate that some items within the scale were measuring the same thing. However, it is also likely to be inflated simply by the large number of items included. Item-test correlations ranged between .39 and .85.

Finally, continuous scales were created for each section of the CAARMS as described in the previous chapter. Since each severity score is effectively weighted by the frequency score this produced a non-additive scale that was not appropriate for testing directly with alpha. However, for Chapter 10, analyses were conducted using only the severity scores, so these scales could be assessed as before. The positive symptoms (4 items, α = .74), negative symptoms (3 items, α = .74) and general psychopathology (8 items, .75) scales all showed an acceptable level of internal consistency.

6.4 Data analysis

6.4.1 Assumption checking

Prior to analysis, the distribution of any continuous measures was explored in order to check for outliers and assess whether basic assumptions of parametric testing were met, including assumptions of normality and homogeneity of variance. This would have implications for the type of statistical tests that could be used in order to reduce the likelihood of erroneously interpreting results. In particular, it was expected that measures of psychopathology conducted on a general population sample would be likely to yield high levels of positive skew (the majority of individuals receiving low scores for little or no symptoms and a small minority receiving much higher scores). Data were examined graphically using histograms and quantile-quantile plots to look for skew, kurtosis and any other variations in distribution. Box plots were used to investigate the presence of outliers and to visually assess differences in variance between groups. Sample sizes were relatively large (>30), meaning that the impact of violations of normality and homogeneity of variance was greatly reduced (Field, 2013). Therefore visual checks were deemed adequate for assessing whether assumptions were met.

Where deviations from a normal distribution were found, attempts were first made to transform the data using methods described by Tabachnick & Fidell (2013) in order that parametric testing might be performed on the transformed variables. If transformation could not resolve these issues then variables were either categorised (usually dichotomised) or used

only for nonparametric testing. Parametric tests were preferred because they are more powerful than nonparametric tests (providing the underlying assumptions are met) and easier to interpret because they use raw scores rather than ranked data. Importantly, parametric tests also provide confidence intervals, which indicate the precision with which estimates about the population are made.

6.4.2 Statistical testing

Once assumptions had been checked, descriptive statistics were obtained for the variables of interest. Categorical data were described in terms of frequencies and percentages. Means and standard deviations were reported for continuous variables that followed a broadly normal distribution. Where data were unusually distributed or contained outliers that may obscure the interpretation, variables were instead described using medians and interquartile ranges. Descriptive statistics were often also stratified by group.

Associations between pairs of categorical variables were primarily assessed using Pearson's chi-squared tests of independence (Pearson, 1900). The validity of this test relies on the sample size being large enough that in a contingency table between the two variables each cell is expected to be populated by five or more observations. In cases where this was not true, Fisher's exact test (Fisher, 1922) was used as an alternative as it was specifically designed to overcome this problem and provides an accurate *p* value even with small samples.

Associations between a continuous outcome variable and a binary predictor variable were assessed using Student's independent samples t-test (Gosset [Student, pseud.], 1908), providing that assumptions of normality and equal variance were not seriously violated. Serious violations of normality, such as high levels of skew or the presence of outliers prompted the use of nonparametric Mann-Whitney U tests (Mann and Whitney, 1947), which make no assumptions about the underlying distribution of the data. Since sample sizes tended to be greater than 30, the *z*-statistic is reported rather than the *U*-statistic.

Multiple linear regression analyses were used to evaluate associations between a continuous outcome variable and one or more predictor variables, while controlling for one or more potential confounders. Logistic regression was used to do the same for analyses in which the outcome variable was binary. Both types of analyses assume a linear (or loglinear, respectively) relationship between variables and that the errors are normally distributed and have equal variance. However, both tests are relatively robust to violations of these assumptions when sample sizes are large (Field, 2013). Where there was clustering of variables, estimates were calculated based on cluster-correlated robust standard errors, using the *vce(cluster clustvar)* option in Stata (Rogers, 1993). This produces robust standard errors,

which allow for correlation within each cluster, and provides additional protection against the violation of assumptions.

Models were built sequentially. First, unadjusted analyses were conducted, then associations were controlled for *a priori* confounders: age (continuous), sex (binary), and ethnicity (white, Black, other) where appropriate. Finally, additional explanatory variables were included to elucidate specific associations where there was reason to suspect additional confounding. Since the statistical power of logistic regression reduces as the number of predictors increases, the number of confounders included was dependent on sample size. These analyses were generally used for specific hypothesis testing so the significance of individual predictors is reported. Wald tests were used to assess the contribution of a single predictor or a group of predictors to a model because although likelihood ratio tests may be more reliable they are not suitable for models based on robust standard errors.

6.4.3 Reporting statistical significance and effect magnitude

In line with current conventions, all *p* values reported were two-tailed and the acceptable likelihood of committing a Type I error was set at 5% ($\alpha = .05$). Nevertheless the arbitrariness of this cut-off was acknowledged and as such exact *p* values are reported, except when these are lower than .001 to three decimal places. It is also recognised that *p* values are greatly influenced by sample size and that true effects may not be detected if a sample is too small, so where smaller samples and subgroups are examined trends that do not reach statistical significance may also be commented on. To aid interpretation, 95% confidence intervals are reported for odds ratios, beta coefficients and prevalence estimates, indicating the range of values within which the true population value is 95% likely to fall. Where statistical power is low confidence intervals are wide and indicate less precise estimates. In such circumstances particular attention is paid to the more conservative range of the estimate.

Wherever possible, objective measures of standardized effect size are also reported to demonstrate the magnitude of associations and to provide comparability across testing. Formulae for all effect sizes are presented in Appendix C (p.244) but justifications for the effect size measures chosen are outlined here. For chi-squared tests, Cramer's V (ϕ_c) is reported (Cramér, 1946). This can take values between 0 (no effect) and 1 (perfect effect) and was chosen over other methods because it is not limited to comparisons based on 2 x 2 contingency tables, although it is noted that ϕ_c does increase as the discrepancy between rows and columns increases. Pearson's *r* is reported for Mann-Whitney U tests and for t-tests. This is the most appropriate for Mann-Whitney tests and was preferred over Cohen's *d* for t-tests because of the additional comparability this would allow across tests. Linear regression also

provides *t*-statistics from which *r* could be calculated for individual predictors. The *r*-statistic has the same parameters as ϕ_c and Cohen (1988) has suggested the following guidelines for both effect sizes as an aid to interpretation: 0.1 = small effect, 0.3 = medium effect, 0.5 = large effect. In addition, *r* is easily converted to R^2 which measures the proportion of the variance in the outcome that is explained by the given effect.

The magnitude of effects from logistic regression was presented in terms of odds ratios (OR), which describe the change in odds of a given outcome that is associated with a single unit change in the independent variable (often comparing one group to another). These are relatively intuitive and are presented with 95% confidence intervals to demonstrate the precision with which these estimates are made. Finally, the effect size for whole logistic regression models was calculated using Tjur's coefficient of discrimination (*D*), which is a simple and intuitive alternative to traditional attempts to recreate the R^2 statistic described above (Tjur, 2009). Tjur's *D* can take values from 0 to 1 and "describes the model's ability to discriminate between successes and failures." (Tjur, 2009, p. 369)

6.4.4 Multiple testing strategy

When several tests are conducted in relation to a single hypothesis the probability of making a Type I error (α) is inflated. In order to prevent the familywise error rate from exceeding the specified level (α = .05) adjustments were made for multiple testing using Hochberg's step-up procedure (Hochberg, 1988). This was developed from the well-known Bonferroni correction, in which alpha is divided by the total number of tests, but provides much greater statistical power and is widely considered to be an improvement of Bonferroni's approach (e.g. Bender and Lange, 2001; Rodger and Roberts, 2013; Shaffer, 1995). For simplicity and to avoid misinterpretation of results, *p* values themselves are corrected so that statistical significance is consistently evaluated against α = .05.

6.4.5 Survey weights

To ensure that the study sample was representative of the population, the study sample was standardised using inverse sampling probability weights. These reduce the potential impact of sampling bias, making results more reliable and generalisable. Weights were constructed based on differences between features of the sample obtained (age, sex and ethnicity) and features of the study population (based on data from the UK Census). The procedure for an individual with characteristics *a*, *b* and *c* was as follows:

$$Weight = \frac{P(a) in\ population}{P(a) in\ sample} \times \frac{P(b) in\ population}{P(b) in\ sample} \times \frac{P(c) in\ population}{P(c) in\ sample}$$

For example, *a, b* and *c* might be male, white and aged 18-27. In this way demographic groups would receive different weighting according to the degree to which they had been under- or over-sampled. These weights were then applied to subsequent analyses.

6.5 Reporting and interpretation: a note on terminology

This area of research is inundated with terms, which may be used casually and interchangeably in some circumstances, but may have subtly different meanings, connotations or certain assumptions attached to them. As such, it is pertinent to acknowledge these and to be clear what is meant by a few important terms which are used in this thesis.

i. Ultra high risk

Throughout this thesis the term ultra high risk (UHR) is used to signify individuals who have met PACE and/or Basic Symptom criteria on the basis of the symptoms they have reported. It must be acknowledged that the term 'ultra high risk' literally implies that the individual is at substantially greater risk of developing psychosis (within a relatively short space of time) than most other individuals. Currently there is no evidence that this is the case for the individuals who are identified this way in the community, since no follow-up studies have been conducted on this specific population. Moreover, psychotic experiences in the general population have been linked with slightly elevated risk for psychotic disorder (Kaymaz et al., 2012) but the absolute risk is still very small compared with conversion rates reported by prodromal services (Fusar-Poli et al., 2012). It can also be argued that the actual risk associated with UHR patients is not only from the severity and frequency of the symptoms experienced but also from the recent decline in functioning and from the act of help-seeking itself, specifically from specialist services – aspects that were necessarily suspended for the purposes of this study. Nevertheless, to use such a specific definition of this group would be to outlaw the possibility of anyone being UHR before they have arrived in services, since this would be a contradiction in terms. Moreover, a substantial proportion of cases present at first episode psychosis services without having been seen by prodromal services. The implication then is that there are potentially individuals who are at UHR out in the community and if one attempts to actively seek and identify them, one cannot wait for them to present at services. Consequently, the reason for using the term 'UHR' is to signify that the individuals identified in this way may well be these hypothesised individuals, who could be conceived as being in the same group as those currently seen in UHR services. The purpose of this research was to begin to test this hypothesis. Finally, the UHR terminology has been used in a similar way in other studies that have identified these symptoms in the community (Kelleher et al., 2012d).

ii. Symptoms

Some authors have justifiably drawn important and meaningful distinctions between psychotic experiences and psychotic symptoms (van Os et al., 2009). While I will attempt to assess the clinical relevance of the phenomena that are identified in this thesis, I have decided not to draw the same linguistic distinction. When I refer to 'symptoms' in my analyses chapters I am including positive endorsement of relevant items to any degree, including mild subclinical levels. The assumption is that 'experiences' are phenotypically continuous with 'symptoms' and as such the same associations are likely to apply to some extent at all levels. Moreover, it is not the aim of this thesis to define a boundary for this distinction. Rather it is the aim to evaluate to some degree the boundary that has already been implied by current UHR criteria.

iii. Common mental disorder

'Common mental disorder' refers to a range of disorders characterised by symptoms of anxiety and depression. This may be thought of categorically but also dimensionally (e.g. Goldberg, 2012) where it is more or less synonymous with 'general psychopathology'. Therefore throughout the thesis I will use the two terms more or less interchangeably when referring to a continuous dimension of depressive/anxious symptoms, and refer specifically to 'a common mental disorder' to denote the binary presence of a diagnosable anxiety/depressive disorder. However, in the analysis sections, these two terms are more specific: 'common mental disorder' is a binary outcome measured using the CIS-R (as in Chapter 3), while 'general psychopathology' is a dimension rated using the CAARMS (see Chapter 5, p.78).

IV. RESULTS

CHAPTER 7 RESULTS (1) – MADNESS IN THE METHOD: HOW REPRESENTATIVE OF THE GENERAL POPULATION IS THE SAMPLE OBTAINED?

7.1 Aims

The first challenge for defining the prevalence of those meeting UHR criteria in the general population lies in recruiting a suitably representative general population sample. The primary aim of this chapter therefore is to present the overall sample that was obtained in the present study and to assess its representativeness in relation to UK Census data for the same catchment area. I will describe how survey weights have been produced in order to account for differences between features of the sample obtained and features of the study population, and adjust for these in the analyses. The second aim of this chapter is to look at the impact of using two different sampling methods, in order to investigate whether there were systematic differences in the characteristics of the samples that they produced and whether the use of multiple methods has produced a less biased sample than a single method would alone. The final aim of this chapter is to examine the nested longitudinal sample and to look for the obvious presence of large amounts of missing data or non-random attrition between SELCoH I and SELCoH II. Analyses conducted within this chapter were exploratory and no specific hypotheses were tested. Nevertheless, potential implications for the interpretation of results are discussed.

7.2 Analytic strategy

Key demographic variables were used to compare the obtained sample with population data for the catchment area from the 2011 UK Census. Frequencies and unweighted percentages are presented for both and chi-squared tests were used to assess the statistical significance of any discrepancies. Age comparisons relate specifically to the age group specified in the present study's inclusion criteria. These comparisons were used to create inverse sampling probability weights, using the process described in Chapter 6 (p.92).

Detailed descriptive statistics are presented for the sample obtained, using frequencies and percentages (weighted and unweighted) for categorical variables and means and standard deviations for continuous variables. Where data were unusually distributed or contained outliers that may obscure the interpretation, medians and interquartile ranges are presented as an alternative. HAM-A, HAM-D and GAF scores are presented as continuous. However, the

HAM-D scores were also examined using the cut-offs recommended by Zimmerman et al. (2013)[2], for additional interpretative value. Lifetime psychotic and depressive experiences were measured dimensionally using the CAPE. However, these overall dimension scores are difficult to interpret so data are presented categorically in terms of the severity of items endorsed.

Exploratory analyses were conducted to examine whether the sample characteristics varied on the basis of the sampling method used. The characteristics selected had been previously been linked with both psychotic experiences and psychotic disorder (van Os et al., 2009). The statistical significance of group differences in continuous variables was assessed using a Student's t-test for normally distributed data and a Mann-Whitney U test where data was non-normally distributed. For Mann-Whitney tests the *z* statistic is reported rather than the *U* statistic because of the relatively large sample sizes. Chi-squared tests were used for most categorical comparisons, but Fisher's exact *p* values were reported where tabulations included one or more expected cell frequencies of less than 5. Associations with continuous and binary outcome measures were tested using regression and logistic regression analyses respectively, both of which allowed for the additional adjustment for potential confounders where appropriate. Both unadjusted and adjusted coefficients are presented. Since analyses were explicitly defined as exploratory and any differences would highlight potential issues rather than confirming pre-specified hypotheses, no adjustments were made for multiple testing (Bender and Lange, 2001).

Finally, the nested longitudinal subsample was compared with the original SELCoH I sample to assess any differences in attrition in relation to key demographic variables. Comparisons were made between the actual sample obtained and an estimated subsample of SELCoH I who were eligible to take part in the present study[3]. Again, chi-squared tests were used for categorical variables and a Mann-Whitney U test was used for age.

Analyses were conducted using Stata 11.2. For statistically significant results, effect sizes are provided using Cramer's V (ϕ_c) for chi-squared tests and Pearson's *r* for Mann-Whitney U tests. These were calculated by hand (for formulae see Appendix C, p.244) and interpreted as recommended by Cohen (1988)[4].

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[2] HAM-D 17-item scores: None 0–7; Mild 8–16; Moderate 17–23; Severe ≥24

[3] This represented all those who would have been aged 18-35 years at some point during the recruitment time for the present study (1st July 2011 – 31st December 2013), calculated using date of birth.

[4] 0.1 = small effect, 0.3 = moderate effect, 0.5 = large effect

7.3 Results

7.3.1 Representativeness and survey weights

In total 208 participants were recruited to the study sample. The sample was then compared to UK Census data for 2011 (shown in Table 7.1). In terms of basic demographics, the sample appeared to be relatively representative in most instances. There was a slightly higher proportion of women (52%) in the sample than might be expected, although this amounted to less than two percentage points (50% in the 2011 Census) and was not statistically significant: $\chi^2(1) = 0.20$, $p = .653$. There were some discrepancies in terms of ethnicity, with particularly high numbers of Black African (18%) and Black Caribbean (12%) participants (compared with 14% and 8% in the Census) and a lower proportion of participants of 'other' (7%) or 'mixed' (4%) ethnicity than might be expected (10% and 7% in the Census respectively). Nevertheless, these differences were all relatively minor and did not reach statistical significance [$\chi^2(5) = 10.79$, $p = .056$], despite the very large sample size. The age distribution within the sample varied slightly from the census, with younger people overrepresented in the sample (47%) compared with the census (43%), but again this was not statistically significant: $\chi^2(1) = 1.21$, $p = .272$. Finally, there was no significant difference noted in terms of economic status, with very similar proportions being economically active within the sample (77%) and the population (75%). On the basis of these findings, inverse sampling probability weights were created for age, sex and ethnicity in order to correct for slight discrepancies from the Census population data and thereby improve the representativeness of the sample.

7.3.2 Describing the sample

Descriptive details of the sample are shown in Table 7.2, which also shows that the application of sampling weights made only minor changes to the proportions in the sample. The sample obtained in the present study had a relatively even gender balance (52% women) and had a mean age of 27 years (*SD* =4.89), although the ages of participants spread across the full range that the intake criteria would allow. There was a high degree of ethnic diversity, with White British ethnicity making up less than half of the sample (41%). The largest ethnic minority group was Black African, which made up just under one fifth of the sample (18%), although weighting the data reduced this.

Table 7.1 Comparing the study sample with 2011 UK Census for the SELCoH study catchment area

	2011 UK Census [a]		Present study sample				
	n (%)		*n* (%)		χ^2	*df*	*p*
Total samples [b]	*N*=591,369		*N* = 208				
Gender							
Male	293,539	(49.6%)	100	(48.1%)	0.20	1	.653
Female	297,830	(50.4%)	108	(51.9%)			
Ethnic group							
White	329,374	(55.7%)	110	(52.9%)	10.79	5	.056
Mixed	40,938	(6.9%)	9	(4.3%)			
Black-Caribbean	46,860	(7.9%)	25	(12.0%)			
Black-African	82,600	(14.0%)	38	(18.3%)			
Asian or Asian British	35,483	(6.0%)	11	(5.3%)			
Other	56,114	(9.5%)	15	(7.2%)			
Age groups [c]							
18-26 years	97,981	(43.3%)	98	(47.1%)	1.21	1	.272
27-35 years	128,110	(56.7%)	110	(52.9%)			
Economic status							
Active [d]	347,049	(75.1%)	159	(76.8%)	0.21	1	.648
Inactive [e]	115,232	(24.9%)	48	(23.2%)			

[a] South east London Boroughs of Lambeth and Southwark; data are provided by the UK Office for National Statistics

[b] Frequencies may not add up to 100% due to missing values; percentages are unweighted

[c] Census sample includes all ages 16-74 years but for age comparison with present study sample only 18-35 year range is presented

[d] Economically active includes: Full time work, Part time work, Casual work, Unemployed, and Working Students

[e] Economically inactive includes: Student, Permanent sick/disabled, Temporary sick, Retired, Looking after children at home

One third of subjects were first generation migrants (*n* = 70), hailing from 39 different countries across six continents (full details in Appendix D, p.246), most commonly from Africa (*n* = 24) and Europe (*n* = 23). Among first generation migrants, the median number of years lived in the UK was 8, although this ranged between 1 and 27 (IQR = 4–15), while the subjective level of fluency in English was generally high (Mdn = 9, IQR = 7–10). The majority of

the sample was currently in employment (full time or part time; 64%) and approximately one fifth of the sample were in full time education (21%). The sample was relatively well educated, with 60% having obtained a university degree, and applying weights slightly increased this to 64%. The mean estimated IQ for the sample was slightly above average at 106 (*SD* = 19.48) and was normally distributed throughout the sample, with four individuals scoring over 140 and three individuals scoring 70 or less. Participants tended to be living with others (87%) and over half were currently married or in a stable relationship (57%). Approximately 40% of participants (*n* = 84) had a first degree relative who had suffered from a mental disorder (as measured by the FIGS), although just fourteen individuals (7%) reported having a first degree relative who had been diagnosed specifically with a psychotic disorder. Just over three fifths of the sample (61%) had used cannabis at some point in their lives and more than one fifth of the sample (22%) reported being a current user. The mean age of first use was 16 years (*SD* = 3.15) and regular use (current use at least once a week) was present in fifteen individuals (7%). Finally, exposure to childhood trauma was rare within the sample. CTQ scores were skewed towards the minimum (Mdn = 1.24, IQR = 1.08 to 1.64) and only 8 individuals (4%) had an overall CTQ score of 3 or above.

Table 7.2 Demographic, environmental and genetic characteristics of the present study sample (N = 208)

	Median (IQR)	**Mean (*SD*)**	**Range**
Age in years	27 (23–31)	27.0 (*4.89*)	(18 – 35)
IQ *(14 missing values)*	106 (91–121)	105.9 (*19.48*)	(58 – 151)
Childhood trauma (CTQ)	1.24 (1.08–1.64)	1.46 (*0.55*)	(1.00 – 3.96)
	n	**% (unweighted)**	***% (weighted)***
Sex			
Male	100	(48.1%)	*(50.8%)*
Female	108	(51.9%)	*(49.2%)*
Employment status			
Employed	133	(63.9%)	*(67.2%)*
Economically inactive	5	(2.4%)	*(2.5%)*
Student	44	(21.2%)	*(19.2%)*
Unemployed	26	(12.5%)	*(11.0%)*
Living status *(1 missing value)*			
Alone	27	(13.0%)	*(13.4%)*
With one other	72	(34.8%)	*(37.1%)*
With multiple others	108	(52.2%)	*(49.5%)*

Highest level of education			
Higher	125	(60.1%)	*(63.7 %)*
Further	63	(30.3%)	*(27.0%)*
School	20	(9.6%)	*(9.3 %)*
Relationship status			
In a stable relationship	119	(57.2%)	*(59.6%)*
Single [a]	89	(42.8%)	*(40.4%)*
Ethnicity			
White British	85	(40.9%)	*(43.3%)*
White Other	25	(12.0%)	*(12.8%)*
Black African	38	(18.3%)	*(13.7%)*
Black Caribbean	25	(12.0%)	*(8.0%)*
Asian (all)	11	(5.3%)	*(5.9%)*
Other	24	(11.5%)	*(16.3%)*
Migrant status			
Born in UK	138	(66.3%)	*(66.1%)*
Born outside of UK	70	(33.7%)	*(33.9%)*
Family history of mental disorder			
None	124	(59.6%)	*(59.6%)*
Psychosis	14	(6.7%)	*(6.3%)*
Other mental disorder	70	(33.7%)	*(34.1%)*
Cannabis use *(7 missing values)*			
Never	78	(39.2%)	*(44.7%)*
Past user (lifetime)	77	(38.7%)	*(33.8%)*
Current user	44	(22.1%)	*(21.5%)*

[a] includes divorced, separated or widowed

Descriptive statistics for recent anxiety, depression and functioning are shown in Table 7.3. The majority of the sample scored low in the past seven days for anxiety (*M* = 5.43, *SD* = 5.46) and depression (*M* = 4.13, *SD* = 4.36), although a few individuals scored much higher and consequently the measures had 36- and 24-point ranges respectively. Eighty-five percent of participants were judged to have no recent depression, 14% as experiencing mild or moderate depression, and just one individual as meeting the threshold for severe depression. The vast majority of participants tended to be functioning well. Average scores were similar for psychological functioning (*M* =75.25, *SD* = 10.72) and social / occupational functioning (*M* = 79.01, *SD* = 10.84). These scores, although not high, indicate the absence of lasting functional impairment in all but a few. GAF-F scores of 50 or less, representing significant functional impairment according to the PACE criteria, were present in just four individuals (2%).

Table 7.3 Recent psychopathology and functional impairment in the present study sample (*N* = 208)

Measure (timescale) *Clinical feature (scale)*	*n*	Mean	(*SD*)	Range
Hamilton rating scales (past 7 days)				
Anxiety (0-56)	207	5.43	(5.46)	(0 – 36)
Depression (0-53)	207	4.13	(4.36)	(0 – 24)
GAF (current)				
Psychological functioning (0-100)	204	75.25	(10.72)	(40 – 98)
Social / occupational functioning (0-100)	204	79.01	(10.84)	(45 – 96)

Isolated lifetime psychotic experiences (as measured by the CAPE) were not uncommon within the sample (Table 7.4), although overall dimension scores were low [Mdn (IQR): Positive dimension = 1.25 (1.10 to 1.45), negative dimension = 1.50 (1.29 to 1.71), depressive dimension = 1.50 (1.38 to 1.75)]. Almost one fifth of the sample (19%) reported one or more severe positive psychotic experience(s) at some point in their life, while 13% reported a severe negative psychotic experience and just 10% of the sample endorsed a depressive item as severe. Again, the application of survey weights changed these proportions very little.

Table 7.4 Lifetime psychotic experiences in the present study sample (N = 208)

Community Assessment of Psychotic Experiences				
Dimension	Total		unweighted	*weighted*
Most severe item endorsed	*n*	*n*	(%)	*(%)*
Positive psychotic dimension	205			
None / Mild		116	(56.6%)	*(59.6%)*
Moderate		50	(24.4%)	*(24.2%)*
Severe		39	(19.0%)	*(16.2%)*
Negative psychotic dimension	205			
None / Mild		111	(54.1%)	*(54.2%)*
Moderate		67	(32.7%)	*(33.3%)*
Severe		27	(13.2%)	*(12.5%)*
Depressive psychotic symptom score	205			
None / Mild		138	(67.3%)	*(65.9%)*
Moderate		48	(23.4%)	*(25.1%)*
Severe		19	(9.3%)	*(9.1%)*

7.3.3 Comparing recruitment methods

The two sampling methods used in recruiting the sample were compared in terms of demographic characteristics, family history of mental disorder and cannabis use. Four of the twelve comparisons made revealed statistically significant differences ($\alpha = .05$) between the two subsamples produced (shown in Table 7.5). The clearest difference was in the recruitment of first generation migrants, which made up 43% of participants sampled through GPs but only 23% of those sampled using PAF: $\chi^2(1) = 9.21$, $p = .002$, $\phi_c = .210$. In the GP subsample the majority of participants were currently in a stable relationship (65%) whereas in the PAF subsample those currently in a relationship made up a slight minority (48%): $\chi^2(1) = 6.29$, $p = .012$, $\phi_c = .174$. There was also a statistically significant difference in age between the subsamples [$z = -2.11$, $p = .035$], although the magnitude of difference was small: $r = .146$. Finally, there was a significant difference in ethnicity between the subsamples: *Fisher's exact* $p = .034$. In particular, GP sampling recruited fewer participants of 'other' (6% v 18%) and Black Caribbean ethnicity (9% v 16%) and more who identified as 'white other' (15% v 8%).

Table 7.5 Sociodemographic and genetic characteristics stratified by sampling method (*N* = 208)

	PAF sampled (*n* = 96)		GP sampled (*n* = 112)				
	Median	(IQR)	Median	(IQR)	*z*	*df*	*p*
Age in years	25	(22–32)	28.5	(24–31)	-2.11	206	.035
Childhood tauma (CTQ) *(1 missing value)*	1.28	(1.10–1.68)	1.24	(1.08–1.60)	0.77	205	.443
	Mean	**(*SD*)**	**Mean**	**(*SD*)**	***t***	***df***	***p***
IQ *(13 missing values)*	103.7	(19.21)	107.8	(19.60)	-1.46	193	.147
	n	**(%)**	***n***	**(%)**	**χ^2**	***df***	***p***
Sex							
Male	42	(43.8%)	58	(51.8%)	1.34	1	.248
Female	54	(56.3%)	54	(48.2%)			
Employment status							
Employed	55	(57.3%)	78	(69.6%)	-	-	.116 †
Economically inactive	4	(4.2%)	1	(0.9%)			
Student	21	(21.9%)	23	(20.5%)			
Unemployed	16	(16.7%)	10	(8.9%)			
Living status *(1 missing value)*							
Alone	17	(17.9%)	10	(8.9%)	4.09	2	.129
With one other	29	(30.5%)	43	(38.4%)			
With multiple others	49	(51.6%)	59	(52.7%)			
Highest level of education							
Higher	51	(53.1%)	74	(66.1%)	3.62	2	.164
Further	34	(35.4%)	29	(25.9%)			
School	11	(11.5%)	9	(8.0%)			
Relationship status							
In a stable relationship	46	(47.9%)	73	(65.2%)	6.29	1	.012
Single	50	(52.1%)	39	(34.8%)			
Migrant status							
Born in UK	74	(77.1%)	64	(57.1%)	9.21	1	.002
Born outside of UK	22	(22.9%)	48	(42.9%)			

Ethnicity							
White British	38	(39.6%)	47	(42.0%)	-	-	.034 †
White Other	8	(8.4%)	17	(15.2%)			
Black African	15	(15.6%)	23	(20.5%)			
Black Caribbean	15	(15.6%)	10	(8.9%)			
Asian (all)	3	(3.1%)	8	(7.1%)			
Other	17	(17.7%)	7	(6.3%)			
Family history of mental disorder							
None	58	(60.4%)	66	(58.9%)	2.50	2	.286
Psychosis	9	(9.4%)	5	(4.5%)			
Other mental disorder	29	(30.2%)	41	(36.6%)			
Cannabis use *(9 missing values)*							
Never	33	(36.3%)	45	(41.7%)	4.07	2	.130
Lifetime (not current)	32	(35.2%)	45	(41.7%)			
Current user	26	(28.6%)	18	(16.7%)			

† Fisher's exact *p* value reported (where any expected cell frequencies) < 5

Based on previous associations with psychotic experiences, the differences just described might be expected to lead to differences in the presence of psychotic experiences and other psychopathology between the samples. Three of the four significant associations (more likely to be younger, single and of non-white ethnicity, Black Caribbean in particular) might predict that psychotic experiences would be more prevalent among the PAF sample than in the GP sample. This was tested in relation to lifetime psychotic experiences, recent common mental disorder and current functioning using a series of regression analyses, the results of which are shown in Table 7.6. None of the measures examined showed any significant differences between the sampling methods. The finding that first generation migrant status was more prevalent within the GP subsample than the PAF subsample, and was the most strongly associated with the sampling method, might predict a relationship with psychotic experiences in the opposite direction to the other three associations. It was therefore possible that these associations could counterbalance one another. The regression analyses were consequently repeated with migrant status included as a confounder and the results are again shown in Table 7.6. Once again there was no evidence for a difference in these measures according to sampling method.

Table 7.6 Psychopathology and functional impairment by sampling method (PAF = 0, GP = 1)

	Unadjusted				Adjusted †			
	β	*df*	*t*	*p*	β	*df*	*t*	*p*
HAM -A	-0.57	205	-0.75	.457	-0.87	204	-1.11	.266
HAM- D	-0.67	205	-1.10	.271	-0.90	204	-1.45	.147
CAPE positive	-0.02	203	-0.66	.508	-0.05	202	-1.35	.178
CAPE negative	-0.02	203	-0.44	.660	-0.04	202	-0.78	.437
GAF-S	1.35	202	0.90	.371	2.09	201	1.38	.170
GAF-F	-0.47	202	-0.31	.756	0.52	201	0.34	.734

† Adjusted for migrant status

Finally, sampling method was investigated as a predictor of various psychotic symptoms at UHR criteria level within the preceding three months. The results of logistic regression analyses are shown in Table 7.7. Again there was no evidence for an association between sampling method and criteria for attenuated positive symptoms, basic symptoms or attenuated negative symptoms, before or after adjustment for migrant status.

Table 7.7 Attenuated psychotic symptom criteria by sampling method (PAF = 0, GP = 1)

	Unadjusted				Adjusted †			
Criteria	β	*SE*	*z*	*p*	β	*SE*	*z*	*p*
APS	-0.83	0.53	-1.57	.117	-0.89	0.54	-1.63	.102
BS	-0.17	0.52	-0.32	.748	-0.35	0.54	-0.65	.518
ANS	-0.52	0.49	-1.07	.286	-0.77	0.51	-1.50	.133

† Adjusted for migrant status

APS = Attenuated positive symptoms, BS = Basic symptoms, ANS = Attenuated negative symptoms

7.3.4 Longitudinal sample characteristics

The nested longitudinal sample within the present study sample was recruited as part of SELCoH II. The recruitment process and relationship between SELCoH I, SELCoH II and the present study is shown in Figure 7.1. There was a high degree of attrition and the final sample recruited for the present study (*n* = 89) represents around 12% of all eligible participants from SELCoH I (*n* ~ 719). The largest proportion of those who could not be recruited were lost at the SELCoH II recruiting stage (*n* = 337), either unable to be contacted or refusing to take part. A further 160 individuals were deemed ineligible to take part in the present study by the SELCoH study team. This encompassed a number of reasons including other members of the same

household already being recruited, previous diagnosis of a psychotic disorder or the receipt of anti-psychotic medication, or having been already included in too many other research modules ahead of the present study. In total, 217 SELCoH participants were invited to take part in the present study, of which 67 could not be contacted again by the present study recruitment team and 59 refused to take part in the present study, most often due to their limited availability. Of the 91 interviews conducted with SELCoH participants, 2 were discontinued when it emerged that the participant had already experienced a first episode of psychosis[5]. Both participants were excluded from the present study sample.

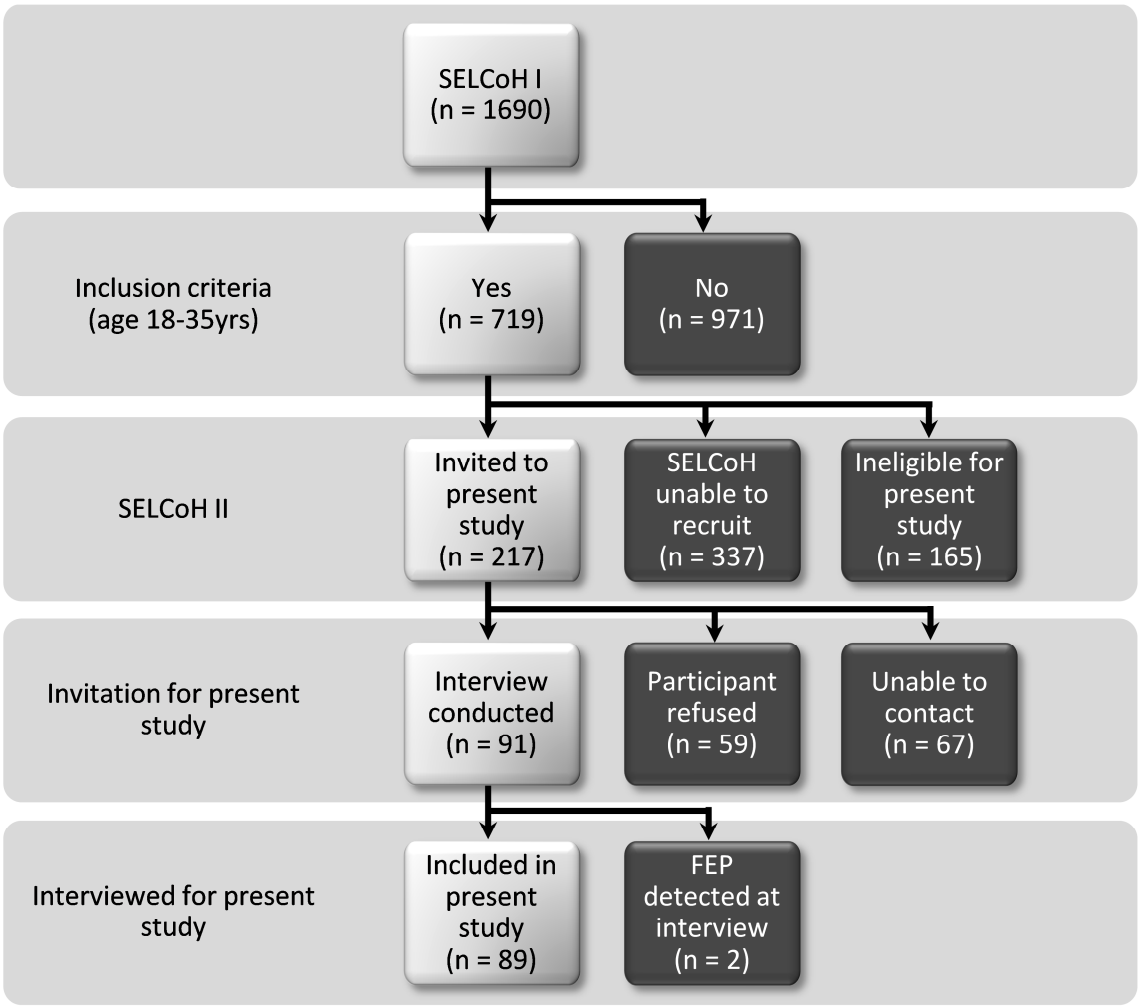


Figure 7.1 Longitudinal sample recruitment process via SELCoH

[5] One of these had also received treatment through the OASIS service and was the only individual interviewed who had done so.

Characteristics of the resultant sample are displayed alongside those of the original SELCoH I sample in Table 7.8. For a more accurate comparison, the subsample of eligible participants (according to the age criterion) is shown along with the full SELCoH I sample. In particular, the proportions of white to minority ethnicities and economically active to economically inactive status are far more similar between the age-matched groups than with the full SELCoH I sample. Direct comparisons between participants who were followed up and eligible participants who were not followed up revealed that attrition was not significantly associated with sex [χ^2 (1) = 0.26, p = .613], ethnicity [χ^2 (4) = 6.15, p = .188] or economic status: χ^2 (1) = 0.09, p = .759. There was, however, a significant association with age as those who were followed up tended to be younger (Mdn = 23yrs) than those who were not (Mdn = 25yrs): z = 2.80, p = .005. Nevertheless the magnitude of this difference was again very small: r = .103.

Table 7.8 Comparison of SELCoH samples

	Entire SELCoH sample *n* (%)		SELCoH sample eligible for follow-up [a] *n* (%)		SELCoH sample followed up *n* (%)	
Total samples	*N*=1698		*N* =733		*N* = 89	
Gender						
Female	959	(56.5%)	410	(55.9%)	52	(58.4%)
Male	739	(43.5%)	323	(44.1%)	37	(41.6%)
Ethnic group						
White	1051	(63.4%)	417	(56.9%)	46	(51.7%)
Black-Caribbean	143	(8.7%)	62	(8.5%)	13	(14.6%)
Black-African	234	(13.2%)	114	(15.6%)	16	(17.9%)
Asian or Asian British	63	(3.5%)	26	(3.5%)	2	(2.3%)
Other	205	(11.2%)	114	(15.6%)	12	(13.5%)
Economic status						
Active [b]	1125	(69.5%)	495	(67.7%)	59	(66.3%)
Inactive[b]	494	(30.5%)	236	(32.3%)	29	(33.7%)
	Median	**(IQR)**	**Median**	**(IQR)**	**Median**	**(IQR)**
Age at baseline	37.0	(26–51)	25.0	(21–29)	23.0	(19–29)

[a] Estimated sample based on projected age (16-35years) on July 1st 2011 (when data collection for the present study began, lasting two years)

[b](see footnotes [d-e] on Table 7.1)

7.4 Discussion

The primary aim of this chapter was to assess the representativeness of the obtained study sample in relation to the catchment area population and of the longitudinal sample in relation to the original SELCoH sample. Secondly, I hoped to examine the impact of using multiple sampling methods and to explore any systematic differences between these approaches. The results I have presented have shown the study sample to be generally representative on all accounts and suggest that although there may be differences between the samples produced from different methods, these do not seem to translate into meaningful differences in the outcomes of interest and thus do not weaken the study.

Representativeness

Comparisons with the 2011 UK Census data for the area showed the sample to be highly representative of the target population based on key demographic variables. The lack of statistically significant differences found was particularly reassuring given that the very large sample size involved in the comparison would make it more likely that even a small effect would be detected. Small differences in ethnicity could be easily corrected by applying sampling weights and were thus unlikely to distort any results, particularly as ethnic minority groups tended to be over- rather than underrepresented within the sample. Indeed, applying these weights to the more detailed sample characteristics showed just minor changes between the weighted and unweighted proportions. This is very encouraging for the interpretation and generalisability of any results based on the sample.

Some characteristics of the sample are worthy of comment. The demographic diversity has been represented well within the sample. For example, London has a much higher proportion of non-UK born residents than the rest of the UK, figures from 2009 estimate this to be around 34% (Gildley and Jayaweera, 2010, p. 26), which exactly matches the distribution in the present sample. This large proportion is also very positive for providing statistical power with which to test associations between psychotic features and ethnic and migrant groups. The level of English language ability did not impair any interviews but may have had an impact on the IQ scores, since the WAIS is standardised to a particular population and contains concepts such as ‘a dozen’ which some individuals found difficult.

Nevertheless, the overall IQ in the sample was slightly above average and the sample was generally well educated. This could reflect a slight selection bias in that more educated individuals might be more interested in being part of a research study. However, the high number of subjects with university degrees or currently in fulltime education may also reflect

increasing levels of university attendance in the UK in recent decades. The fact that IQ scores were normally distributed in the sample suggests that if this effect was present it was only minor. It was a surprise to find three individuals with an estimated IQ score of 70 or less as this is widely considered to be the threshold for an intellectual disability, which might merit exclusion from the study. However, these three scores were in the range 67-70, so it is difficult to be confident enough in the precision of the estimate (based on a shortened version of the assessment) to opt for exclusion. Furthermore, the fact that no participants had given the impression of having intellectual disabilities during the assessment process is reassuring for this decision. Estimated IQ scores will be interpreted with caution nonetheless.

Symptom levels and environmental exposures in the sample were both in line with what was expected. Recent and lifetime psychotic experiences and depression was relatively common at very low levels and rare at severe levels, although present in a few. Similarly, serious functional impairment was present only in a few individuals. Family history of mental disorder was present for 2 in every 5 participants, although this tended most often to be depression and only 14 subjects had a first degree relative with psychosis. Similarly, lifetime cannabis use was reported by over half of the sample but of those who were classed as current users, very few used cannabis regularly.

Recruitment methods

The UK postal address file (PAF) and GP patient lists are two sources which, if used as frameworks for random sampling, should produce epidemiologically rigorous and representative samples. The comparisons presented here show that on the majority of demographic and environmental characteristics examined there were no significant differences between the two. Nevertheless, the samples produced were not identical and did differ on characteristics that have previously been linked to psychotic experiences and psychotic disorder.

The most striking difference was that PAF sampling identified fewer migrants than the GP approach, but there are a number of reasons why this is likely to have occurred. One major factor is that the PAF sample is primarily populated by SELCoH participants who were first recruited approximately three years prior to the present study. In resampling existing participants it is possible that migrants were subject to more attrition, since they may have only had short term visas or may not have intended to stay in the UK long-term; Vargas-Silva (2014) reports that around 45% of migrants only intend to stay in the UK for 1-2 years. Anyone intending to remain in the UK for at least 3 months can register for a GP and it may be that migrants would be particularly likely to do so since free NHS healthcare is one of the UK's most attractive features. The ethnic differences between the samples are also likely to be related to

this; given that a large proportion of first generation migrants in the sample were from Africa, it is unsurprising that GP sampling also identified a greater proportion of Black African subjects. Conversely, the PAF approach identified a greater proportion of Black Caribbean subjects, who are now more likely to be second or third generation migrants given peak immigration for this group occurred in 1960s.

Participants sampled through PAF were on average less than two years younger and were more likely to be single than those sampled through GP lists. The reasons for this are unclear, although it is possible that these represent more disorganised individuals who may be less likely to have registered for a GP. Alternatively, these individuals may be more likely to be home and more willing to answer the door and take part in research, while older individuals in stable relationships may be more likely to respond to a letter sent through their GP. Nevertheless, the effect sizes for these differences were small.

Ultimately none of these differences in sample characteristics translated into any differences in measured psychopathology. The key message from this is that different sampling methods have the potential to produce systematic differences in the type of individuals they identify. Depending on the focus of the research these differences may be directly important for the outcome, although in this case there is no evidence that they had an effect. In this sense either method may have been adequate to produce a representative sample. Nevertheless, the use of both methods is likely to have enabled access to some individuals who may have been otherwise excluded and the present sample may be more representative as a result.

Longitudinal follow-up

While it would have been desirable to recruit a larger longitudinal sample, the fact that the obtained longitudinal sample was generally representative of the eligible subset of SELCoH I participants on the basis of key demographics is still encouraging. Those followed up were significantly younger on average, but only by two years, which is unlikely to have a large impact. This is also inflated because the eligible subset was estimated based on anyone who would be within the eligible age range at any time during recruitment. This included any individual who was aged 35 on the first day of recruitment, meaning that during this two year period several potential participants would have exceeded the age range and could no longer be interviewed. Thus there is more chance that the oldest would not have been followed up. However, since I had no control over when SELCoH interviewed and passed on participants this could not be avoided. Finally, although there were some small differences in other variables, particularly in terms of ethnicity, these were not statistically significant and were unlikely to affect future analyses especially when weights were applied.

Limitations

Although the sample obtained appeared to be demographically representative, there is always the possibility that there may be important differences on variables that were not measured. In this way there is always the opportunity for selection bias; for example, based on levels of symptoms or functioning, for which no data were available for the population. However, this is true of any such study. Although direct comparisons with UK Census data were limited by the comparability of available data, the descriptive statistics presented in this chapter appear to be within what would be expected for the population in terms of migration, unemployment and other characteristics that are known to be associated with psychosis.

The comparison between sampling methods is useful but is limited to some degree by the time difference in original recruitment dates. As discussed, key differences between the two methods such as in the identification of migrants could be partially or wholly explained by this time aspect, which weakens any conclusions about the type of people they are likely to recruit and thus any wider implications beyond the scope of this thesis. However, for the present purposes it is sufficient to demonstrate that the differences between the methods are few and that the overall sample obtained through this combination of approaches is representative of the target population.

Finally, the attrition rate of 88% of the eligible sample from SELCoH I was disappointing and is potentially problematic. A primary cause of this is the number of individuals who were no longer contactable or who refused to take part in SELCoH II, but there is little that could have been done about this. Moreover, great care was taken to make contact with participants and to be as flexible and accommodating as possible, yet the number who could not be recruited to the present study was still high. The fact that the longitudinal sample still appeared to be representative on basic demographic measures is reassuring. However, any conclusions drawn in relation to the longitudinal sample will remain cautious.

Conclusion

The results presented this chapter have demonstrated that the primary aim of obtaining a sample that is highly representative of the target population and close to the size specified has been achieved. This provides a good grounding for the rest of the study and should enable findings and conclusions to be generalised to the population, while the nested longitudinal subsample will extend the range of questions that can be investigated.

CHAPTER 8 RESULTS (2) – CAARMS IN THE COMMUNITY: WHAT IS THE PREVALENCE OF THE ULTRA HIGH RISK STATE IN THE GENERAL POPULATION?

8.1 Aims and hypotheses

The primary aims of this chapter are to a) estimate the prevalence of individuals meeting UHR criteria in the general population; b) investigate the relationship between this and the prevalence of occasional psychotic experiences; and c) examine whether both the UHR syndrome and psychotic experiences are associated with risk factors for psychotic disorders. In attempting to achieve this, a number of different UHR criteria are adopted and compared in order to question the reliance on positive symptoms, assess the consistency of the different approaches and to explore the implications of any differences that may exist. In particular the focus is on the PACE criteria, assessed by the CAARMS, and the Basic Symptom criteria (BS), assessed by the SPIA-9. However, I will also consider separately the experimental criteria for an additional attenuated negative symptoms (ANS) group. The prevalence of past-year psychotic experiences within this sample was assessed at the same time point using the PSQ to provide a baseline point of comparison for this sample against previous samples reported in this thesis.

I tested the following hypotheses:

H_1 The prevalence of those meeting symptomatic UHR criteria in the community will be lower than that of isolated psychotic experiences (around 18% in the SELCoH sample; Morgan et al., 2014) but higher than that of psychotic disorders (around 3%; Binbay et al., 2012; Perala et al., 2007).

H_2 While some UHR subjects will meet both the PACE criteria and the BS criteria, there will also be subjects who meet only one set of criteria.

H_3 UHR status will be associated with similar demographic and environmental risk factors to psychotic disorder. Specifically, UHR status will be more prevalent among:

a. Males (McGrath et al., 2004)
b. Ethnic minorities, particularly those of Black ethnicity (Sharpley et al., 2001)
c. First generation migrants (Cantor-Graae and Selten, 2005)
d. Victims of childhood trauma. (Read et al., 2005)
e. Cannabis users (Henquet et al., 2005)

H_4 The UHR syndrome will be more prevalent among those who have previously reported a psychotic experience, especially if this re-occurred or persisted, or was reported in the context of a common mental disorder.

8.2 Analytic strategy

Descriptive statistics for the CAARMS and the SPIA-9 were first examined to explore the distribution of various psychotic phenomena within the sample. Severity scores of 3 or above were considered to indicate the presence of a symptom of at least moderate level, while lower scores were seen as indicating a mild symptom or anomalous experience. Inverse sampling probability weights for age, sex and ethnicity (described in Chapter 6, p.92) were applied in order to make the sample more representative of the target population and to improve the validity of any conclusions. The 12-month prevalence of psychotic experiences was calculated along with the 3-month prevalence of subjects meeting various UHR criteria. Point estimates and 95% confidence intervals are reported. The frequency and overlap between those meeting PACE criteria and BS criteria was then explored, along with the proposed criteria for ANS.

A series of hypothesis-driven logistic regression analyses were carried out to test for associations between known risk factors for psychotic disorder and UHR status in the community. Exploratory analyses were then conducted on PACE and BS UHR criteria separately in order to observe any differences in their associations with risk factors. Associations with ANS were also examined. Risk factors were selected on the basis of literature review findings (discussed in Chapter 2). Since 'current cannabis use' included all individuals who had ever tried cannabis and would not rule out using again, associations with cannabis use were assessed using the variable for regular cannabis use (past or present) and controlling for current use. All associations were adjusted using age, sex, ethnicity and unemployment as a priori confounders where appropriate. Sex comparisons were also adjusted for symptoms of common mental disorder (as indexed by the CAARMS general psychopathology section score), which are known to be more prevalent in women than men.

Further analyses were conducted using the nested longitudinal sample (n = 88), examining the influence of psychotic experiences reported at time 1, the co-presence of common mental disorder and persistence of psychotic experiences over time. These analyses focused on UHR status as the primary outcome, defined as meeting either the PACE or BS criteria (or both). Nevertheless, the reduced number of cases in this subsample restricted the use of multivariable statistics (only age was used as a confounder), and the resulting analyses were primarily descriptive and univariable.

Analyses were conducted using Stata 11.2. All percentages and analyses are weighted unless otherwise specified.

8.3 Results

8.3.1 Psychotic symptoms in the general population

Around 38% of participants (*n* = 86) reported at least one mild positive symptom within the last three months. Twenty four percent (*n* = 53) reported one or more positive symptom(s) reaching moderate severity, or experienced at least once a month for over an hour or three times per week for under an hour. Responses to each of the subscales in the first section of the CAARMS are laid out in Table 8.1. Non-bizarre ideas (including paranoia) and perceptual abnormalities (including hallucinations) were the most common experiences, each present to some degree in 17-18% of the sample (both *n* = 168). Unusual thought content was the least common, reported to some degree by just 10% of subjects (*n* = 20).

Table 8.1 Frequency of UHR symptoms as measured by the CAARMS (N=208)

	Absent		Mild		Present	
	n	(%)	*n*	(%)	*n*	(%)
Unusual thought content						
Global severity	188	(90.1%)	12	(5.6%)	8	(3.4%)
Frequency	188	(90.1%)	11	(4.7%)	9	(4.3%)
Non-bizarre ideas						
Global severity	168	(82.4%)	29	(13.2%)	11	(4.4%)
Frequency	168	(82.4%)	17	(7.6%)	23	(10.0%)
Perceptual abnormalities						
Global severity	168	(82.6%)	17	(8.4%)	22	(9.0%)
Frequency	168	(82.6%)	23	(9.8%)	16	(7.5%)
Disorganised speech						
Global severity	177	(86.6%)	24	(10.9%)	6	(2.8%)
Frequency	177	(86.6%)	17	(7.4%)	13	(6.3%)
Total (one or more symptom(s))	-	-	86	(38.3%)	54	(23.9%)

Note: All percentages are weighted

CAARMS scores: 0 = Absent; 1-2 = Mild; 3+ = Present

At the mild severity level, non-bizarre ideas were the most common (*n* = 29, 13%), followed by disorganised speech (*n* = 24, 11%), while perceptual abnormalities were most likely to occur with a low frequency (*n* = 23, 10%). In contrast, perceptual abnormalities occurred the most at higher severity (*n* = 22, 9%) and was the only experience to be present more often with higher severity than with mild severity. When non-bizarre ideas were reported they most commonly occurred at a high frequency (*n* = 23, 10%). Disorganised speech was the least reported to be present at higher severity (*n* = 6, 3%), followed closely by unusual thought content (*n* = 8, 3%).

Table 8.2 Frequency of basic symptoms as measured by the SPIA-9 (*N*=208)

	Absent		Mild		Present	
	n	(%)	*n*	(%)	*n*	(%)
Unstable ideas of reference	160	(78.2%)	44	(20.3%)	4	(1.5%)
Thought interferences	176	(85.6%)	11	(4.7%)	21	(9.8%)
Thought blockages	138	(68.1%)	43	(20.0%)	27	(11.9%)
Thought pressure	194	(93.6%)	7	(3.5%)	7	(2.9%)
Captivation of attention by details	199	(95.5%)	5	(2.3%)	4	(2.2%)
Disturbance of expressive speech	184	(89.3%)	12	(5.3%)	12	(5.4%)
Disturbance of receptive speech	203	(97.2%)	2	(1.1%)	3	(1.7%)
Disturbances in abstract thinking	205	(98.7%)	2	(0.8%)	1	(0.5%)
Inability to divide attention	202	(96.9%)	3	(1.5%)	3	(1.6%)
Total (one or more symptom(s))	-	-	86	(40.8%)	59	(26.7%)

Note: All percentages are weighted

SPIA-9 scores for each symptom: 0 = Absent; 1-2 = Mild; 3+ = Present

Fifty nine individuals (27%) reported the presence of one or more basic symptom(s) according to the SPIA-9, and 86 individuals (41%) reported at least one mild symptom. Responses to all SPIA-9 items can be seen in Table 8.2. The endorsement of basic symptoms was not evenly spread, with disturbances in abstract thinking, disturbances in receptive speech and an inability to divide attention being particularly rare at all levels (range: *n* = 1-3, 0-2%). On the other hand, mild unstable ideas of reference and thought blockages were each reported in at least 20% of the sample (*n* = 44, 43 respectively), while more severe thought blockages and

thought interferences were present in 12% (*n* = 27) and 10% (*n* = 21) of the sample respectively. While many basic symptoms were reported by a similar (low) proportion of the sample at both severity levels, more severe thought interferences were almost twice as prevalent (*n* = 21, 10%) as mild thought interferences (*n* = 11, 5%). The opposite was true of unstable ideas of reference, which showed the greatest disparity in prevalence between mild (*n* = 44, 20%) and higher severity basic symptoms (*n* = 4, 2%).

Table 8.3 Prevalence of psychotic experiences and UHR (n=208)

	Frequency *n* (unweighted %)		Estimated weighted prevalence(95% CI)	
Psychotic experiences:				
PSQ	32	(15.4%)	13.8 %	(9.8-19.2)
Negative symptoms:				
ANS	19	(9.1%)	9.3 %	(5.9-14.3)
Ultra High risk subgroups:				
APS	17	(8.2%)	6.9 %	(4.2-10.9)
BLIPS	0	(0%)	-	-
GRD	2	(1.0%)	0.9 %	(0.02-3.6)
TOTAL PACE	**18**	**(8.7%)**	**7.3 %**	**(4.6-11.5)**
BS	16	(7.7%)	7.1 %	(4.3-11.5)
TOTAL UHR	**30**	**(14.4%)**	**12.6 %**	**(8.8-17.7)**

ANS = Attenuated negative symptoms, APS = Attenuated positive symptoms,
BLIPS = Brief limited intermittent psychotic symptoms, BS = Basic symptoms,
GRD = Genetic risk and decline, PSQ = Psychosis screening questionnaire
PACE = APS, BLIPS or GRD criteria met, UHR = PACE + BS criteria met
Note: Percentages may not add up as individuals may fall into multiple UHR groups

8.3.2 Estimating the prevalence of the UHR state

Eighteen individuals (from a sample of *n* = 208) met the symptomatic threshold for an UHR state according to the traditionally used PACE criteria (see Table 8.3), leading to a weighted prevalence estimate of 7.3% (95% confidence interval: 4.6 to 11.5). This is substantially lower than the prevalence of isolated psychotic experiences, which were almost twice as prevalent

(13.8% weighted prevalence, 95% CI: 9.8 to 19.2), although there was a slight overlap between the confidence intervals.

When BS criteria were considered in addition to PACE criteria, 30 individuals met the symptomatic threshold for an UHR state (12.6% weighted prevalence, 95% confidence interval: 8.8 to 17.7). Within the UHR group, 17 individuals met PACE criteria for attenuated positive symptoms (6.9% weighted prevalence, 95% CI: 4.2 to 10.9) while 16 subjects met criteria for basic symptoms (7.1% weighted prevalence, 95% CI: 4.3 to 11.5). Finally, just two individuals met criteria for a genetic risk and decline (0.9% weighted prevalence, 95% CI: 0.0 to 3.6) and no individuals met PACE criteria for brief intermittent limited psychotic symptoms.

In addition, 19 individuals met the experimental criteria for attenuated negative symptoms (9% weighted prevalence, 95% CI: 5.9 to 14.3).

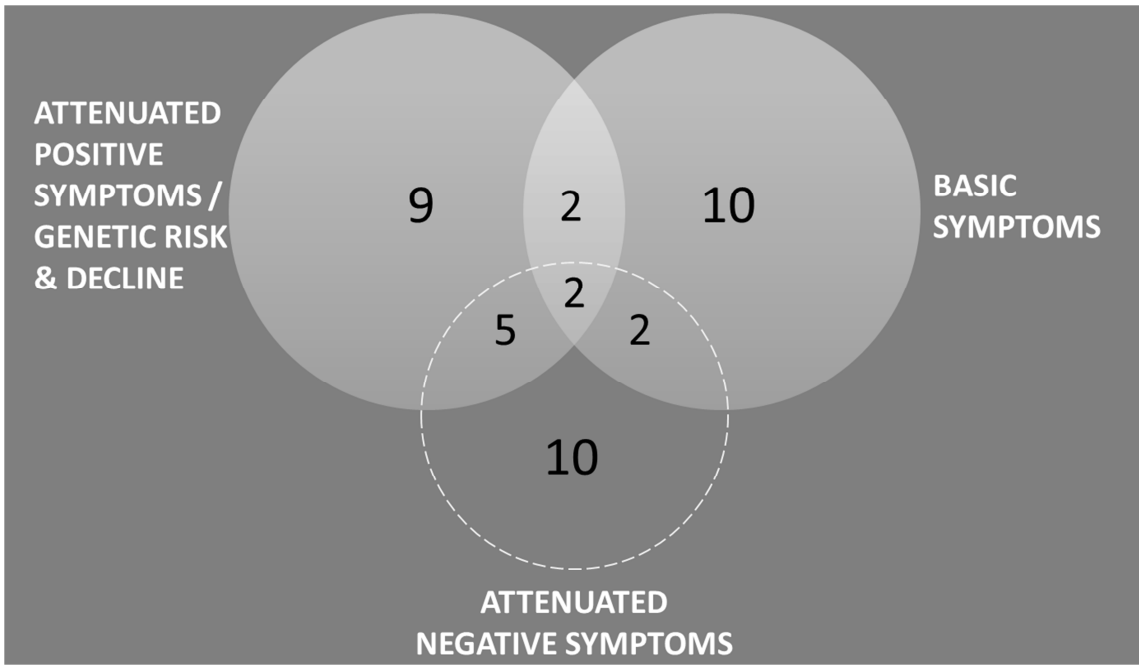


Figure 8.1 Venn diagram showing frequency of individuals across attenuated psychotic symptoms

8.3.3 Comparing ultra high risk features

Thirty individuals were identified as meeting symptomatic criteria for UHR. The number of individuals with different types of attenuated psychotic symptoms is shown in Figure 8.1. It can be seen clearly that there was some overlap between the different sets of criteria. For example, four individuals met both the PACE and BS criteria. The largest overlap fell between the PACE UHR (primarily attenuated positive symptoms) group and those with ANS, with seven individuals having both positive and negative symptoms. Nevertheless, Figure 8.1 illustrates the fact that the largest proportion of individuals within each group did not meet multiple

criteria; almost three quarters of individuals identified were only experiencing one type of psychotic feature. Moreover, of the 30 individuals meeting UHR criteria, 26 were uniquely identified by one set of criteria. Put another way, they would not have been identified if that particular set of criteria not been included. For the current sample, reliance on the PACE criteria alone would have led to 40% of UHR individuals (who met BS criteria alone) not being identified.

8.3.4 Demographic predictors and environmental exposures

Sex differences

There was a statistically significant association between UHR status and sex. Only 6% of men met UHR criteria (*n* = 7) whereas almost 20% women did (*n* = 23). This amounted to an odds ratio of 4.10 after adjustment for a priori confounders (see Table 8.4). Confidence intervals were relatively wide but the lower bounds suggest a minimum odds ratio of around 1.6 in a direction contrary to what was predicted. However, this effect was lessened and the association was marginally nonsignificant after further adjustment for general psychopathology: OR = 2.61, 95% CI: 0.95 to 7.19 (not shown). Exploratory analyses indicated similar odds ratios of around 2 to 3 in relation to the specific attenuated psychotic features (Table 8.4). Only the association with PACE criteria was statistically significant: Adj OR = 3.33. 95% CI: 1.10 to 10.11.

Table 8.4 Associations between UHR status and sex (male = 0, female = 1) (*N* = 208)

Criteria met	OR	*p*	(95% CI)	Adj OR†	*p*	(95% CI)
UHR	3.92	.004	(1.55-9.90)	4.10	.003	(1.63-10.33)
PACE	3.22	.036	(1.08-9.63)	3.33	.034	(1.10-10.11)
BS	3.02	.071	(0.91-10.04)	3.02	.072	(0.91-10.03)
ANS	2.38	.099	(0.85-6.71)	2.61	.080	(0.89-7.62)

† Adjusted for age, ethnicity and unemployment

Ethnic minority status

Ethnic minority status (non-White-British) was examined separately for participants of Black African or Black Caribbean ethnicity and for other minority ethnicity groups. In total, 24 ethnic minority participants (17%) met UHR criteria, compared with only 6 participants who were White British (6%). The proportion was greater among Black African and Black Caribbean participants, with 15 individuals meeting UHR criteria (23%), than among other ethnic

minorities, where 9 subjects (13%) met UHR criteria. Compared with the White British majority group, Black ethnicity was associated with a fourfold increases in the odds of meeting UHR criteria (see Table 8.5), which was slightly reduced and made more precise by adjusting for a priori confounders: Adj OR = 3.38, 95% CI: 1.16 to 9.86. In contrast, other ethnic minorities had slightly less elevated odds (odds ratios in the region of 2 to 3) but the effect was only trending towards statistical significance after adjustment for confounders: Adj. OR = 2.53, 95% CI: 0.86 to 7.49. Exploratory analyses revealed a similar association between Black ethnicity and PACE criteria, although this fell slightly below statistical significance after adjustment, suggesting some confounding may have occurred. However, the other ethnic minority group appeared to be more associated with BS criteria, with an odds ratio of more than three trending towards statistical significance: Adj. OR = 3.39, 95% CI: 0.88 to 13.50. There was no evidence for either minority group being associated with meeting the experimental ANS criteria.

Table 8.5 Associations between UHR status and ethnicity (*N* = 208)

Criteria met							
Minority group		OR	*p*	(95% CI)	Adj OR†	*p*	(95% CI)
UHR							
	Black	4.34	.005	(1.56 -12.08)	3.38	.026	(1.16 -9.86)
	Other	2.35	.129	(0.78 -7.10)	2.53	.093	(0.86 -7.49)
PACE							
	Black	4.08	.024	(1.20 -13.82)	2.98	.086	(0.86 -10.39)
	Other	1.48	.595	(0.35 -6.24)	1.68	.486	(0.39 -7.22)
BS							
	Black	3.01	.134	(0.71 -12.70)	2.57	.241	(0.53 -12.54)
	Other	3.52	.081	(0.86 -14.44)	3.39	.075	(0.88 -13.05)
ANS							
	Black	0.94	.926	(0.25 -3.55)	0.76	.679	(0.20 -2.86)
	Other	2.44	.113	(0.81 -7.40)	2.42	.114	(0.81 -7.27)

Note: White British is comparison group. Black includes Black Caribbean and Black African. Other includes white and other minorities.

† Adjusted for age, sex and unemployment

Migrant status

UHR criteria was met by 17% of first generation migrants (*n* = 12) and 11% of non-migrants (*n* = 18) but there was no evidence that this differed more than would be expected by chance.

Exploratory analysis revealed marginally significant associations with basic symptoms and attenuated negative symptoms with odds ratios again around 3 (see Table 8.6). The association with negative symptoms was strengthened by adjustment for a priori confounders and was statistically significant: OR = 3.11, 95% CI: 1.26 to 7.72.

Table 8.6 Associations between UHR status and first generation migrant status (*N* = 208)

Criteria met	OR	*p*	(95% CI)	Adj OR†	*p*	(95% CI)
UHR	1.68	.213	(0.74-3.83)	1.55	.389	(0.57-4.24)
PACE	1.04	.940	(0.36-3.01)	0.81	.749	(0.21-3.05)
BS	2.85	.051	(1.00-8.17)	3.02	.074	(0.90-10.15)
ANS	2.66	.051	(1.00-7.08)	3.11	.015	(1.26-7.72)

† Adjusted for age, sex, ethnicity and unemployment

Childhood trauma

CTQ scores were generally low throughout the sample (Mdn CTQ score = 1.24, IQR: 1.08-1.64). The proportion of those meeting UHR criteria was much greater among those who scored above the median for exposure to childhood trauma (21%, *n* = 24) than among those who scored below the median (5%, *n* = 6). The association between UHR status and the continuous CTQ score (scale: 1-5) was statistically significant before and after adjustment for a priori confounders (see Table 8.7): Adj. OR = 2.79, 95% CI: 1.17 to 6.68. Results of further exploratory analysis indicated that this association may have been driven most strongly by basic symptoms, which remained significant after adjustment: Adj. OR = 2.66, 95% CI: 1.12 to 6.33.

Table 8.7 Associations between UHR status and childhood trauma (CTQ score) (*N* = 207)

Criteria met	OR	*p*	(95% CI)	Adj OR†	*p*	(95% CI)
UHR	2.81	.001	(1.50-5.28)	2.79	.021	(1.17-6.68)
PACE	2.25	.017	(1.16-4.38)	1.82	.208	(0.71-4.64)
BS	2.38	.009	(1.24-4.56)	2.66	.027	(1.12-6.33)
ANS	1.44	.330	(0.69-2.99)	1.57	.352	(0.61-4.04)

† Adjusted for age, sex, ethnicity and unemployment

Cannabis use

In the present study sample 35 individuals reported having used cannabis once a week or more at some time past or present. A greater proportion of these subjects (22%, *n* = 9) met UHR criteria than of the 136 subjects who had not used cannabis to this degree (9%, *n* = 14). Data on the frequency of cannabis use was missing for 37 individuals. However, this was not associated with UHR status: $\chi^2(1) = 0.74$, $p = .391$. This association was shown to be statistically significant, with the odds of meeting UHR criteria being over three times greater with regular cannabis use [OR = 3.50, 95% CI: 1.25 to 9.75], regardless of whether this was past or present. This association strengthened after adjustment for a priori confounders: OR = 5.07, 95% CI: 1.60 to 16.13. Nevertheless the wide confidence intervals indicate a lack of statistical power to detect this effect with precision and caution should be exercised when interpreting the size of the effect. Finally, additional exploratory analyses indicated that this association was driven almost entirely by a significant increase in the odds of meeting PACE criteria, which again strengthened after adjustment but indicated an even larger degree of error: Adj OR = 7.60, 95% CI: 1.78 to 32.51.

Table 8.8 Associations between UHR status and regular cannabis use (*N* = 171)

Criteria met	Adj OR	*p*	(95% CI)	Adj OR†	*p*	(95% CI)
UHR	3.50	.017	(1.25-9.75)	5.07	.006	(1.60-16.13)
PACE	4.82	.010	(1.45-16.01)	7.60	.007	(1.78-32.51)
BS	1.34	.737	(0.24-7.42)	1.50	.656	(0.25-9.11)
ANS	0.46	.304	(0.11-2.02)	0.45	.327	(0.09-2.26)

† Adjusted for age, sex, ethnicity and unemployment

8.3.5 Longitudinal predictors

Past psychotic experiences

Using the nested longitudinal subsample (*n* = 89) UHR status was found to be associated with psychotic experiences reported approximately three years previously (see Table 8.9). The odds of meeting UHR criteria at time 2 were over four times greater among those who had reported a psychotic experience at time 1 compared to those who had not: OR = 4.09, 95% CI: 1.34 to 12.49. This association remained marginally significant after adjusting for age. Exploratory analyses revealed that this association was largely driven by greater odds of meeting PACE criteria in those who had previously reported a psychotic experience [OR = 3.94, 95% CI: 1.07 to 14.50]. However, after adjusting for age, the association was no longer

statistically significant. There was no evidence that previous psychotic experiences were associated with increased odds of meeting basic symptom criteria or having attenuated negative symptoms.

Table 8.9 Association between psychotic experiences at time 1 and UHR status at time 2 (about 3 years after)

	OR	95% CI	*p*	Adj. OR†	95% CI	*p*
UHR	4.09	1.34-12.49	.014	3.43	1.00-11.75	.050
PACE	3.94	1.07-14.50	.039	3.07	0.76-12.41	.114
BS	2.78	0.61-12.74	.186	2.44	0.40-14.99	.332
ANS	1.85	0.48-7.13	.368	1.70	0.38-7.61	.489

UHR = all those meeting PACE and/or BS criteria

† Adjusted for age

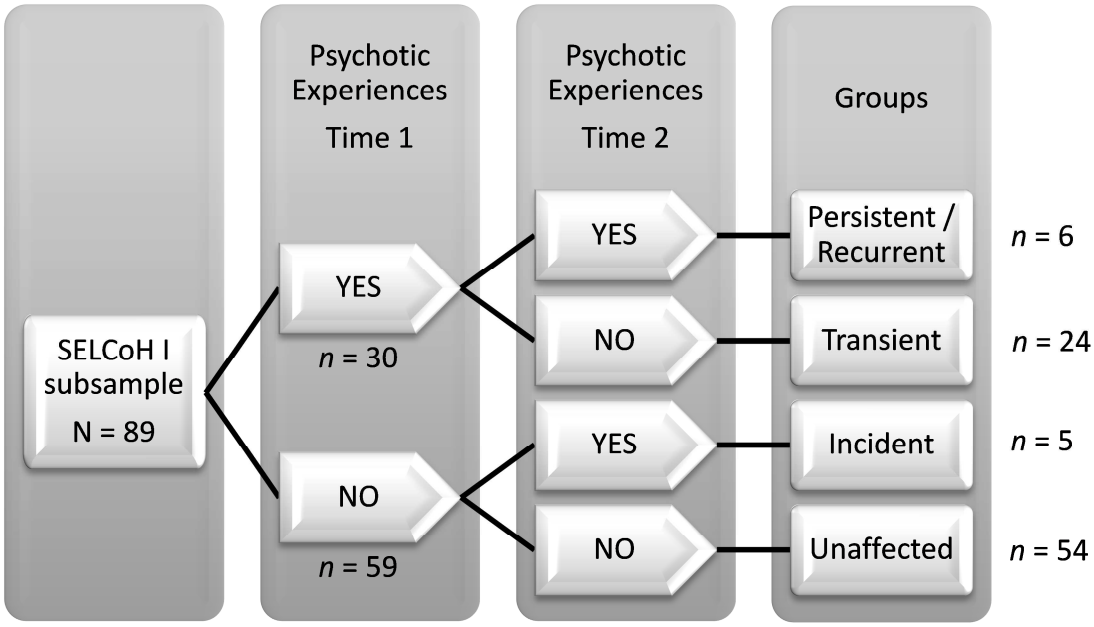


Figure 8.2 Pattern of isolated psychotic experiences over two time points

Persistence of psychotic experiences

Approximately 19% of those who reported a psychotic experience at time 1 also reported a psychotic experience at time 2 (*n* = 6), while the other 81% did not (*n* = 24). The 'incidence' of newly reported psychotic experiences among those who had not reported them previously was low – just under 8% (*n* = 5) – consequently, within this subsample psychotic experiences were more prevalent at time 1 than at time 2. The frequency of psychotic experiences within the longitudinal sample at both time points is displayed in Figure 8.2. The configuration of

these results was used to form four groups: unaffected (no psychotic experiences), transient/remitted experiences, incident psychotic experiences, and persistent/recurrent psychotic experiences.

UHR status was examined in relation to the persistence of psychotic experiences (see Table 8.10). Descriptively there appeared to be a linear trend through the four groups in terms of the proportion who met UHR criteria – least common among those who did not report psychotic experiences on the PSQ at either time point (9%) and most common among the persistent / recurrent group (54%). Odds ratios from logistic regression confirmed this trend: compared to those reporting no psychotic experiences, the odds of meeting UHR criteria appeared to be around four times greater in the transient experiences group (95% CI: 1.20 to 15.78), over seven times greater in the incident group (95% CI: 0.97 to 56.74) and around twelve times greater in the persistent group (95% CI: 1.85 to 79.55). Similarly it should be noted that because of the small numbers in this analysis there was very low statistical power. However, the associations with the transient and persistent psychotic experiences did reach statistical significance and the association with the incident psychotic experiences indicated marginal significance. Nevertheless the confidence intervals for all of these odds ratios are very wide and should be interpreted with extreme caution. Again, owing to the small numbers, this was not analysed further.

Table 8.10 Persistence of isolated psychotic experiences predicts UHR status about 3 years later

	Total	UHR			
Group	*n*	*n*	(%)	OR	95% CI	*p*
Unaffected	54	6	(8.7)	1.00	--	--
Transient	24	7	(29.3)	4.36	1.20-15.78	.025
Incident	5	2	(41.3)	7.41	0.97-56.74	.054
Persistent	6	3	(53.5)	12.14	1.85-79.55	.010

All percentages are weighted

UHR = all those meeting either PACE or BS criteria

Psychotic experiences and common mental disorder

Finally, UHR status at time 2 was assessed against the combination of psychotic experiences and common mental disorder at time 1, as shown in Table 8.11. Again, the numbers were small so the precision of analysis was limited, but there appeared to be a trend in the same direction as observed in Chapter 3. Subjects who had reported both a psychotic experience and a common mental disorder at time 1 were more likely to meet UHR criteria at

time 2 than not, almost a thirteen-fold increase in odds compared with those who reported no symptoms (95% CI: 2.80 to 56.86). However, there was no clear evidence that reporting psychotic experiences or common mental disorder alone was associated with increased odds of meeting UHR criteria at time 2. As with the previous analysis the wide confidence intervals indicate a large potential for error and therefore warrant much caution in their interpretation. Nevertheless, the lower value of the confidence interval indicated that the population odds ratio for those experiencing both a psychotic experience and a common mental disorder is likely to be upwards of 2.80.

Table 8.11 Combination of psychotic experiences and common mental disorder at time 1 predicts UHR status at time 2 (about 3 years later)

	Total	UHR				
	n	*n*	(%)	OR	95% CI	*p*
No symptoms	47	5	(8.7)	1.00	--	--
PE only	17	3	(18.3)	2.36	0.46-12.01	.295
CMD only	12	3	(20.1)	2.66	0.51-14.01	.245
PE+CMD	13	7	(54.4)	12.61	2.80-56.86	.001

All percentages are weighted. UHR = all those meeting either PACE or BS criteria,
PE = psychotic experiences, CMD = common mental disorder

8.4 Discussion

In this chapter I have presented evidence that a small but substantial proportion of individuals in the general population do meet UHR criteria. Using a representative population sample, I have estimated the prevalence of the UHR state (as traditionally defined by meeting symptomatic PACE criteria) among 18-35 year olds in the community to be around 7%. With the addition of the BS criteria, this prevalence estimate was revised to just under 13% - approximately 1 in every 8 individuals. Furthermore this UHR state has been shown to be associated with risk factors that have been previously linked to psychotic disorder. In contrast to clinical findings, the UHR group identified was not characterised primarily by positive symptoms but also to a large degree by basic symptoms. Finally, persistent psychotic experiences, and those reported in the context of a common mental disorder, predicted UHR status about three years later. The context and implications of these findings are now discussed.

Identification of the UHR state

A key strength of this work is that prevalence figures have been produced based on face to face interviews in a representative general population sample. The findings presented here support the idea that the prevalence of individuals meeting UHR criteria in the general population is higher than previously reported prevalence figures for psychotic disorder (Binbay et al., 2012; Perala et al., 2007). Likewise, the prevalence of the UHR state as defined by PACE criteria (7%) was substantially lower than the prevalence of isolated psychotic experiences as assessed by the PSQ (14%) and indeed the 18% reported for the area previously (Morgan et al., 2014). Furthermore, the prevalence estimate of 7% is remarkably comparable to the 8% prevalence reported by Kelleher et al. (2012d) for PACE criteria in a community sample of young adolescents. Given the age difference between the samples (11 to 13 years versus mean 27 years in the present sample) it might be expected that the prevalence in the present study should be lower. However, this may owe in part to the high concentration of risk factors for psychosis present in the South London area (discussed in Chapter 3, p.42). Nonetheless, there is now evidence from two independent community studies that the UHR state, as traditionally defined by the PACE criteria, may be prevalent in around 7% of the general population.

A second key strength of the present study is the inclusion of basic symptoms, producing for the first time an estimate of how basic symptoms are distributed in the general population in relation to other attenuated psychotic symptoms. When the BS criteria were added to the PACE criteria, the estimated community prevalence of the UHR state was raised to around 13%. The prevalence of one or more basic symptoms in the community (27%) is also very close to Meng and colleagues' (2009) finding of 30% for the same in a sample of adolescents. Taken together, the current findings fit well in the context of previous literature. Moreover, the findings reported in this chapter fully support my second hypothesis that there would be individuals who were identified by only one set of UHR criteria. In fact this applied to 26 out of 30 individuals who met UHR criteria. For example, 40% of the UHR individuals identified in the present study had reported basic symptoms alone. This is potentially a very important finding. If basic symptoms are considered to indicate an increased risk for psychosis (Klosterkötter et al., 2001; Schultze-Lutter et al., 2014a) and be burdensome in their own right (Schultze-Lutter, 2009), then this raises the question of whether the current intake criteria for UHR services are appropriately meeting the needs of the communities they aim to serve.

Predictors of the UHR state in the community

Given that the study's inclusion criteria ensured that subjects were all within the age range most at risk for developing psychosis and living in a highly urban area, and that a family history

of psychotic disorder was part of the definition of the UHR state, associations were explored among five other main risk factors for psychotic disorder. These have also been shown to be associated with psychotic experiences less far along the phenomenological continuum (e.g. van Os et al., 2009) so it was expected that many of the same associations would be replicated in the UHR group. Doing so should help to validate these experiences as being part of the same extended psychosis phenotype. The findings reported provide partial support for my remaining hypotheses. As predicted, UHR status was found to be associated with ethnic minority status, childhood trauma and regular cannabis use. However, there was no evidence for an association with first generation migrant status and the association with gender appeared to contradict my hypothesis.

Although exposure to childhood trauma was rare throughout the sample, particularly at severe levels, and there was less data available for the frequency of cannabis use than for other variables, these two risk factors showed the strongest associations with UHR status. While the causal role of childhood trauma in the development of psychosis has been debated (Morgan and Fisher, 2007; Read et al., 2005), it is clear from previous evidence that early trauma is associated with a range of negative outcomes and later disorder (see Norman et al., 2012 for review), making it important from the perspective of identifying individuals in need of care. Interestingly, exploratory analyses presented here suggested that this association may be driven by basic symptoms rather than positive symptoms, adding support to the idea that those with basic symptoms alone may indeed be a vulnerable group.

The association between UHR status and cannabis use is also in line with the literature. Associations have been shown to exist throughout the extended psychosis phenotype (Linscott and van Os, 2013; Radhakrishnan et al., 2014). Cannabis use may also be relatively specific in the risk that it confers, for example early use has been linked to positive symptoms, while frequent heavy use has been linked to negative symptoms (Schubart et al., 2011). Results in the present study seemed to indicate an effect driven mainly by an association with attenuated positive symptoms, showing no association with negative or basic symptoms. Interestingly, the fact that these associations were present even when current cannabis use was controlled could imply that regular use at any time may confer a risk for later psychotic experiences.

Given the relatively stable finding that schizophrenia is more common among men than women (e.g. McGrath et al., 2004) it was surprising to find that UHR status was more prevalent in women. This is also at odds with trends found in community psychotic experiences (van Os et al., 2009) and in UHR clinical services (Fusar-Poli et al., 2013c). However, several other individual studies have noted a similar trend (e.g. Ronald et al., 2014; Yung et al., 2009; Zammit

et al., 2013). The results in the present study suggest that much of this disparity may be attributed to affective symptoms (thought to be more common in women; van Os et al., 2010) since the association was no longer statistically significant after adjusting for general psychopathology scores, a finding similar to that reported by Maric and colleagues (2003). Nonetheless, odds ratios (although not statistically significant after this adjustment) consistently indicated a trend towards a higher prevalence in women. There is therefore no evidence to support my hypothesis of UHR in the community being more prevalent among men.

First generation migrancy has previously been shown to be a risk factor both for psychotic disorder and for (positive) psychotic experiences (Cantor-Graae and Selten, 2005; Linscott and van Os, 2013; McGrath et al., 2004; Morgan et al., 2010). However, previous research has also suggested that this may be driven more strongly by minority status than by migration itself, with stronger associations found for second generation migrants, particularly where their ethnic density is low (Cantor-Graae and Selten, 2005; van Os et al., 2010). The present findings also support the lack of association between migrant status and psychotic experiences in the same catchment area (Morgan et al., 2014: Table DS3, online). In contrast, the association with ethnic minority status was found as expected. The evidence indicated a relatively strong association with Black ethnicity, particularly with positive symptoms, but this may have been confounded in part by unemployment (as in previous studies; e.g. Boydell et al., 2013). In sum, the present results support the idea that ethnicity may be more predictive of UHR status than migrant status per se. The UK has had a greater proportion of migration from EU countries in recent years, whereas the vast majority of migration from the Caribbean and Africa occurred prior to the last decade (Gildley and Jayaweera, 2010, p. 32). Therefore, given the age inclusion for the study it is conceivable that many Black individuals (especially those of Caribbean origin) would be second generation migrants and thus not contribute to an association with migrant status. Meanwhile, the majority of first generation migrants in the sample were not Black, and therefore may have diluted any effect. With the large proportion of migrants living in London, it is also possible that migrants may be less isolated than in other areas, which may be protective against developing psychotic experiences (Das-Munshi et al., 2012).

Longitudinal findings tentatively supported my final hypothesis that previously reported positive psychotic experiences would lead to a greater chance of meeting UHR criteria approximately three years later. However, these were not predictive of later basic or negative symptoms. In line with other research, the increase in the odds of meeting UHR criteria was greatest in the group whose psychotic experience persisted or recurred (e.g. Dominguez et al., 2011). However, with only two time points, measuring ‘persistence' is problematic (as

discussed by Linscott and van Os, 2013) and the sample was too small to draw formal conclusions. Nonetheless the proportion of time 1 psychotic experiences that were transient in the present sample was 80%, which corresponds exactly with the 80% estimate that has been reported in review findings (Linscott and van Os, 2013) and provides some encouragement in these findings.

Furthermore, the odds of meeting UHR criteria were greatly elevated among those who had previously reported psychotic experiences with a concurrent common mental disorder, compared those who previously reported no symptoms. These findings provide tentative evidence that the combination of psychotic experiences and common mental disorder may predict UHR status around 3 years later. This is in line with studies of clinical UHR samples, which indicate a high prevalence of concurrent affective disorders in help-seeking subjects with UHR symptoms (Fusar-Poli et al., 2014b).These results are also consistent with the suggestion that the co-occurrence of common mental disorder and psychotic experiences could encourage distress to accumulate, later triggering the onset of characteristic UHR symptoms that may be associated with help-seeking from prodromal clinics (Fusar-Poli et al., 2014c). For example, anxiety and depressive disorders may further impair the coping strategies of UHR subjects and their ability to function in the social and familiar environment (Fusar-Poli et al., 2014b). This is of particular interest as psychosocial impairment is an independent predictor of longitudinal outcome (Fusar-Poli et al., 2010; Valmaggia et al., 2013). These results may therefore be of some key value in prospectively identifying individuals whose symptoms might persist or progress over time.

Attenuated negative symptoms

An initial examination of the experimental ANS criteria in the general population has been potentially useful. Unfortunately, there is to my knowledge no data on the prevalence of negative symptoms in the general population with which to directly compare these findings (although Dominguez et al., 2010 have estimated the lifetime prevalence of a cluster of negative and disorganised symptoms to be around 16%).However, the finding that as many individuals reported attenuated negative symptoms as reported attenuated positive symptoms could have implications for the way that UHR services target potential patients. While negative symptoms have been shown to be highly predictive of transition to psychosis within the context of attenuated positive symptoms (Demjaha et al., 2010), there is currently no evidence to suggest that such symptoms in isolation would define an individual as being at ultra high risk and the experimental criteria themselves have not been validated. However, these individuals could be of particular concern if they were to develop additional positive symptoms. Therefore

in the interests of early intervention it may be valuable to identify them. In addition, negative symptoms are more resistant to treatment and therefore may significantly impact on the functional and psychosocial status of UHR individuals. However, a major problem with attenuated negative symptoms is their low specificity, as they are also evident in other non-psychotic disorders such as anxiety, depressive or bipolar disorders. The negative symptoms identified in this sample are likely to have had a significant overlap with depression, since the symptoms were rated independently, and as a result the prevalence of the ANS group in this sample is likely to be relatively high and can be seen as a liberal estimate.

Limitations

Interviewing randomly selected members of the population rather than interviewing those who present to UHR clinics means that the seriousness of symptoms is more likely to be diluted with transient symptoms which would have resolved independently. The prevalence of individuals who meet symptomatic UHR criteria at any one time may be a slight over-estimate of the number that would actually be considered to be at-risk. Nevertheless, from a clinical point of view it may be more conscientious to over-identify this group rather than miss individuals who may be in need of care. Moreover, in only measuring experiences from the preceding 3 months rather than the past year, the hope is that more persistent or recurring symptoms would be identified along with far fewer of these transient experiences.

The identification of negative symptoms and basic symptoms is difficult and somewhat experimental. These experiences are usually subjective and hard to verify, and the interview questions relating to these may therefore be more likely to be misinterpreted. In particular, the most common basic symptoms reported were thought blockages and thought interferences, which are both more harder to differentiate from normal experience than, for example, auditory hallucinations. Although care was taken to clarify that symptoms reported met the necessary criteria for inclusion it is possible that the prevalence estimate for these experiences is slightly inflated as a result. Similarly, it is difficult to draw a clear distinction between secondary negative symptoms that are part of depression and primary negative symptoms that are part of the course of psychosis (Carpenter et al., 1985).

Furthermore, no diagnostic information about subjects was available. The understanding of how UHR symptoms are influenced by concurrent common mental disorder would have been enhanced by the inclusion of a scale such as the SCID. Knowing whether participants met diagnostic criteria for axis I disorders such as depression or anxiety, or axis II personality disorders would help to provide more comparability with other populations. In absence of this though, the CAARMS section score for general psychopathology seems a reasonable

substitute, given that it particularly focuses on the same time frame as the psychotic experiences. This is unlike the Hamilton scales, which focus only on the previous week, or the depressive dimension of the CAPE, which takes into account lifetime experiences.

Finally, the results presented here are limited by the sample size. For some, particularly the longitudinal analyses, the confidence intervals are consistently very wide and so the odds ratios reported lack precision. Similarly, while adding confounders to logistic regression models can help to understand relationships, the subsequent reduction in statistical power has to some extent restricted what can be examined. Nevertheless, within the time frame of the thesis this was a necessary trade-off in return for a high quality data obtained through face to face interviews and from an epidemiologically rigorous sample. This represents a methodological step forward compared with previous telephone methods, enabling an interview more representative of clinical practice and allowing additional visual cues to aid the building of rapport and the understanding of symptoms. Therefore, while there may not be sufficient statistical power to fully explore some of the relationships noted in this chapter, these results do provide an important starting point for the understanding of UHR in the general population, upon which the next chapters of this thesis will build.

Conclusion

In this chapter I have identified a group of individuals within a general population sample who meet PACE criteria for the UHR state, and who may represent around 7% of the local community. This is remarkably similar to findings previously reported in the literature. Furthermore, I have shown that the addition of the BS criteria raise the community prevalence of the UHR state up to 13%. I have highlighted that these symptoms may be associated with specific demographic features. However, there may be differences between individuals characterised primarily by basic symptoms and those characterised by positive symptoms. Finally I have provided tentative evidence that UHR status is predicted longitudinally by the conjoint presence of psychotic experiences and comorbid disorders. The important thing to establish next is what membership of this group actually means. For example, are these individuals distressed by their symptoms? Are they functioning any worse than other members of the population? Do these individuals show any inclination to seek help for their symptoms? Knowing the answers to these questions will enable a much greater understanding of how valid this approach is for identifying individuals who are genuinely in need of care.

CHAPTER 9 RESULTS (3) – CAREFREE OR NEED FOR CARE? DISTRESS, FUNCTIONING AND HELP-SEEKING BEHAVIOUR IN THE COMMUNITY ULTRA HIGH RISK GROUP.

9.1 Aims and hypotheses

The previous chapter described and discussed the identification of individuals meeting UHR criteria in the general population. The primary aims of the present chapter are to establish whether these individuals were distressed by their experiences, to what degree there was a need for care and what proportion were already engaged in help-seeking behaviours. If members of the community met UHR criteria then it is possible that these people are in need of clinical help but are not currently receiving it; in other words they represent a genuine unmet need. Alternatively it is possible that meeting these criteria does not necessarily imply such a need and that the group identified is not distressed or in need of care, and is generally functioning well. The former would potentially indicate a need to extend the reach of services and improve intake, the latter would potentially call for a revision of the intake criteria themselves (Schimmelmann et al., 2013). In order to address this issue, I will first examine the functioning, subjective distress and need for care among the community UHR group, compared with the rest of the sample. Next I will look at patterns of help-seeking behaviour in the UHR subgroup, particularly looking for individual characteristics and symptom characteristics that are associated with help-seeking. Finally, I will qualitatively explore the reasons why some individuals might not seek help.

I tested the following hypotheses:

H_1 Those meeting UHR criteria may be distressed by their symptoms and will exhibit worse functioning, lower IQ and a greater need for care than those who do not meet UHR criteria.

H_2 Those meeting UHR criteria will be more likely to be help-seeking than those who do not.

H_3 Within the UHR subgroup, help-seeking behaviour will vary according to both characteristics of the individual and the nature of their symptoms:

a. More help-seeking will be associated with
    i. A family history of mental health disorder;
    ii. Greater severity of symptoms;
    iii. Symptoms that are associated with distress.
b. Less help-seeking will be associated with
    i. Ethnic minority status;
    ii. First generation migrancy;

iii. Lower education.

H_4 Among UHR symptoms, basic symptoms will be less likely to lead to help-seeking behaviour than positive symptoms.

9.2 Analytic strategy

The UHR group was first examined in terms of distress, functioning, IQ and need for care. Distress scores were derived using the average and maximum distress ratings (0-100 scale) from the CAARMS and SPIA-9 and then examined in relation to symptoms of interest. Differences between those who met UHR criteria and those who did not were then assessed using t-tests for distress and GAF scores, with effect size *r* reported for significant results. Cognitive ability (as indexed by full scale IQ) was compared according to UHR status using linear regression, which is robust to slight deviations from normality and allowed level of education to be held constant for the analysis of IQ. Differences in need for care (as assessed by the Camberwell Assessment of Need – Short Appraisal Scale; CANSAS) were also explored between those who met UHR criteria and those who did not. Because of a high degree of skew, scores were categorised into three groups – no needs, met needs only and any unmet needs – and analysed using multinomial logistic regression.

Next, the overall pattern of help-seeking behaviour was examined descriptively in terms of frequencies and proportions, first for the whole sample and then specifically for the UHR subgroup. This included both professional help-seeking (from professional health services) and informal help-seeking (from other sources, such as friends and family). Individuals were categorised as having sought no help, informal help only or any professional help. Multinomial logistic regression was used to assess the relative odds of help-seeking according to UHR status, controlling for a priori confounders, age, sex and ethnicity, and then including general psychopathology as a possible explanatory variable. Results of all contrasts are presented.

Individual characteristics were then examined as predictors of professional help-seeking within the UHR subgroup. Demographic characteristics were chosen on the basis of previously reported associations with psychological help-seeking (Mojtabai et al., 2002) and were coded as binary to maximise cell frequencies. Comparisons are presented descriptively between those who sought professional help and those who did not. The statistical significance of hypothesised differences was assessed using Fisher's exact tests because of the small group sizes. These were not compatible with sampling weights so were conducted on unweighted data. Weighted and unweighted proportions were very similar, so this is likely to be a good approximation. Individual differences in GAF scores and CAARMS section scores were also explored within the UHR group in relation to professional help-seeking. GAF scores were

analysed using t-tests as before. Median scores were compared for CAARMS section scores because of the presence of outliers, which have a disproportionate impact on the mean in small samples. Since nonparametric tests are not compatible with survey weights, Mann-Whitney tests were conducted on unweighted data. Weighted medians and interquartile ranges were almost identical to the unweighted estimates so again this was seen as a good approximation.

Symptom characteristics were examined as predictors of professional help-seeking specifically for that symptom. Help-seeking specifically for positive symptoms, negative symptoms, basic symptoms and general psychopathology is presented descriptively at the individual level for all members of the UHR subgroup. To assess whether the distress associated with a given symptom predicted help-seeking for that symptom, specific help-seeking was examined at the symptom level, that is, analysing across all symptoms reported rather than across individuals. This was achieved using logistic regression analyses with cluster-correlated robust standard error estimation to account for the clustering of symptoms within individuals (see Chapter 6, p.90). Models were built in stages, adding a symptom category variable to the unadjusted model and then a measure of symptom severity to help clarify the associations. To assess whether symptom characteristics predicted help-seeking independently of symptom form, the contribution of the symptom category variable to the final model was assessed using a Wald test. Tjur's coefficient of discrimination (*D*) is provided as the model's effect size.

Finally, reasons for not seeking help were explored qualitatively among those who perceived a help-seeking need but did not act upon it. This group was too small for hypothesis testing so information is presented descriptively. Survey responses were broadly categorised under the following four themes: practical barriers, negative views of professional care, unaware of services and personal concerns. Full information about the items and open-ended responses included in each can be found in Appendix D (p.245).

Quantitative analyses were conducted using Stata 11.2. Inverse survey weights were calculated for sex and ethnicity and applied using Stata's survey commands (as in the previous chapter). Unless specified otherwise, all percentages and analyses are weighted.

9.3 Results

9.3.1 How ill is the UHR group? - Distress, functioning and need for care

The distribution of positive symptoms, basic symptoms negative symptoms and general psychopathology, along with their associated subjective distress, is shown in Table 9.1. Distress scores relate to both the average distress and the most distressing symptom within each

symptom type. For all of these measures, those who met UHR criteria were significantly more distressed by the symptoms they reported than those who did not (all *p*s < .001). Effect sizes were all moderately large, indicating a relatively substantial difference. For both groups, the lowest distress scores were associated with basic symptoms, although this relative difference was clearer in the UHR group than among those who did not meet criteria. Negative symptoms were the least commonly reported and associated with the highest levels of distress in the UHR group. In contrast, the non UHR group were least likely to report positive symptoms, while the single most distressing symptom (maximum) score was highest for general psychopathology.

Table 9.1 Comparison of subjective distress scores (0-100) by UHR status for each symptom type (*N* = 192)

Symptom type							
Distress score	*n*	Mean	(*SD*)	*t*	*df*	*p*	*r*
Positive symptoms[a]							
Average distress							
Non UHR	55	29.9	25.3	4.41	81	< .001	.440
UHR	28	55.6	25.0				
Maximum distress							
Non UHR	55	32.9	27.5	5.46	81	< .001	.519
UHR	28	66.8	27.1				
Basic Symptoms[b]							
Average distress							
Non UHR	82	23.3	20.4	4.68	108	< .001	.411
UHR	28	46.0	23.1				
Maximum distress							
Non UHR	82	28.9	25.0	5.64	108	< .001	.477
UHR	28	59.2	25.5				
Negative symptoms[c]							
Average distress							
Non UHR	80	42.0	23.4	4.20	95	< .001	.396
UHR	17	68.3	24.2				
Maximum distress							
Non UHR	80	44.1	24.7	5.01	95	< .001	.457
UHR	17	74.5	23.7				

Symptom type							
Distress score	*n*	Mean	(*SD*)	*t*	*df*	*p*	*r*
General Psychopathology[d]							
Average distress							
Non UHR	138	40.5	24.1	3.97	166	< .001	.294
UHR	30	60.6	26.2				
Maximum distress							
Non UHR	138	48.5	28.0	4.44	166	< .001	.326
UHR	30	73.6	28.8				

Note: 'symptom' here is the endorsement of any relevant item, even if very mild.

Includes all participants who endorsed one or more symptoms UHR (*n* = 30), non UHR (*n* = 162)

[a] CAARMS (4 items) [b] SPIA-9 (9 items) [c] CAARMS (3 items) [d] CAARMS (8 items)

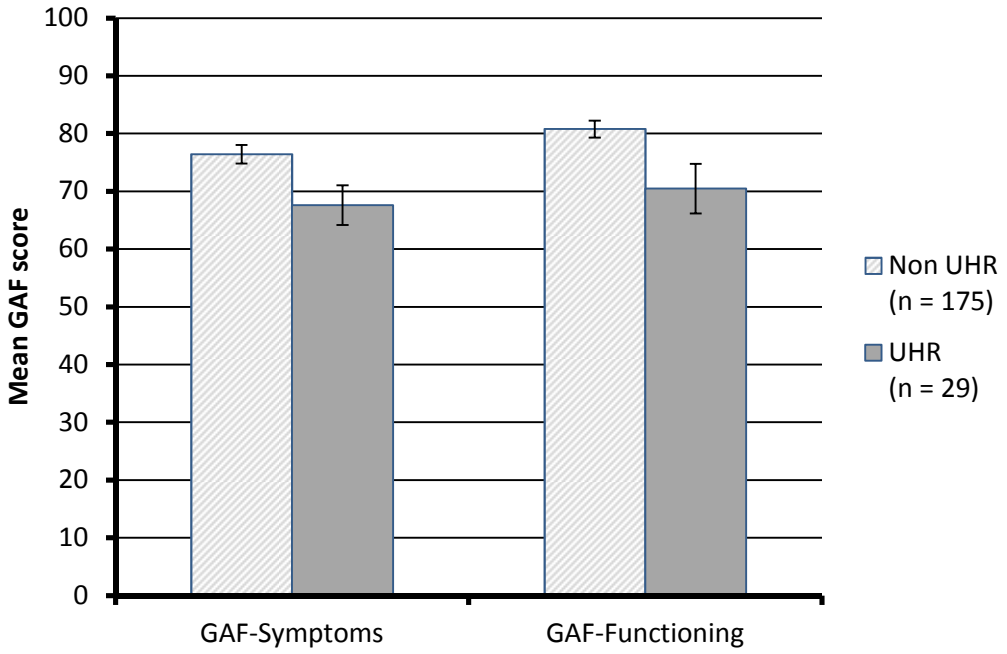


Figure 9.1 Greater functional impairment in the community UHR group

With regard to functioning, GAF-S scores were significantly lower among those who met UHR criteria (*M* = 67.6, *SD* = 9.88) compared with those who did not (*M* = 76.4, *SD* = 10.45): *t*(202) = -4.48, *p* < .001, *r* = .301. Similarly, UHR status was associated with a 10-point drop in GAF-F score: *M* = 70.47, *SD* = 12.39; *t*(202) = -4.45, p < .001, *r* = .299 (displayed in Figure 9.1). Additional exploration of UHR criteria subgroups revealed a descriptive trend for individuals meeting PACE criteria to be more functionally impaired [*M* (*SD*): GAF-S = 65.4 (8.89); GAF-F = 67.6 (11.98)] than those who met BS criteria alone: GAF-S = 70.5 (10.14); GAF-F = 74.1

(11.77). However, the differences between these groups were not statistically significant for GAF-S [$t(202) = -1.41$, $p = .159$] or for GAF-F: $t(202) = -1.46$, $p = .147$.

Cognitive ability was also lower in the UHR group. The mean full scale IQ score in the UHR group was 97.1 (*SD* = 17.25) which was significantly lower than the rest of the sample (*M* = 109.7, *SD* = 18.34): β = -12.61 (95% CI: -19.40 to -5.82), $t(191) = -3.66$, $p < .001$. This association remained significant with level of education held constant: β = -9.14 (95% CI: -16.22 to -2.05), $t(190) = 2.54$, $p = .012$.

Differences in need for care were observed between those who met UHR criteria and those who did not (see Table 9.2). An estimated two thirds (66%) of UHR community subjects reported one or more unmet need(s). Using the tripartite need for care variable, a multinomial logistic regression analysis revealed much greater odds of reporting one or more unmet need(s) among the UHR group [OR = 12.85, 95% CI: 3.94 to 41.96], indicating a greater need for care. No difference was observed in relation to met needs. In addition, no significant differences in need for care were found between those meeting PACE criteria (64.8% have an unmet need) and those meeting BS criteria (67.5% have an unmet need): OR = 1.46, 95% CI: 0.16 to 13.36.

Table 9.2 Multinomial logistic regression of UHR on need for care (*N* = 206)

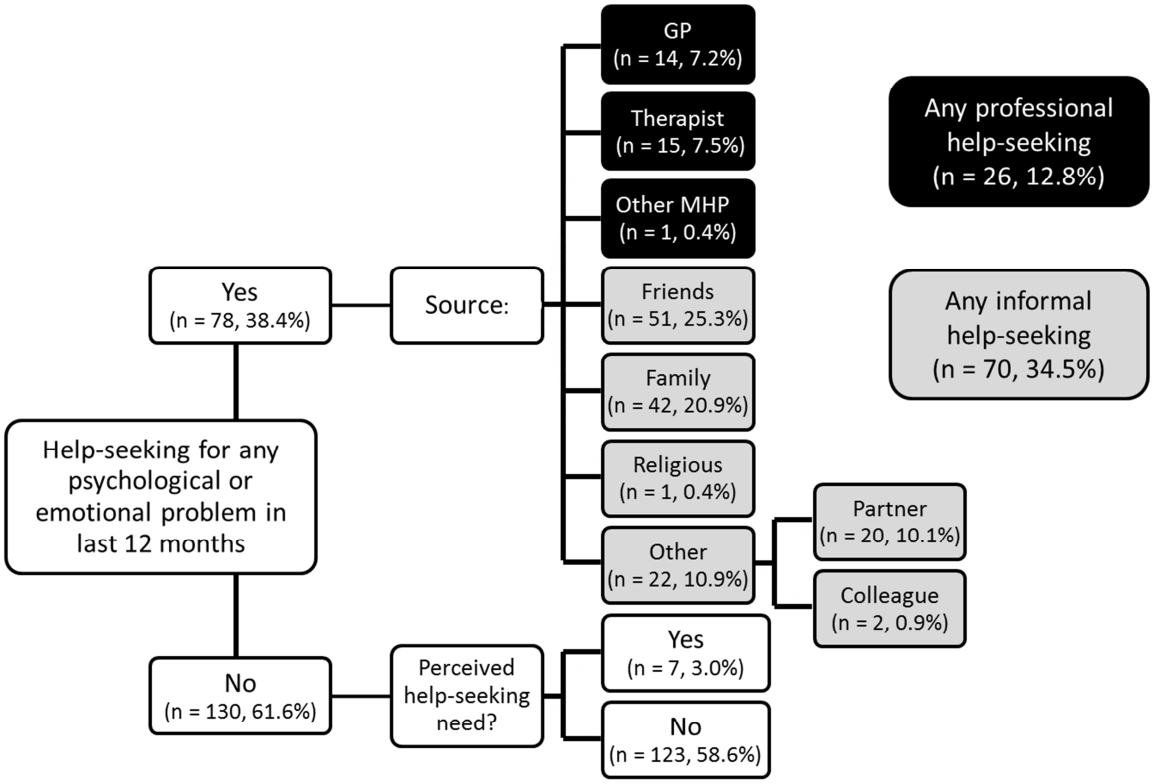
	Total	UHR				
	n	*n*	(column %)	OR	95% CI	*p*
None	89	4	(14.9%)	1.00	--	--
One or more met need(s) only	68	6	(19.1%)	1.85	0.48-7.11	.371
One or more unmet need(s)	51	20	(66.0%)	12.85	3.94-41.96	<.001

Note: percentages are weighted.

9.3.2 What is the overall pattern of help-seeking behaviour?

Help-seeking behaviour was examined for the whole sample using the general help-seeking questions and the resulting pattern of responses is shown in Figure 9.2. Out of 208 subjects, 77 (38%) had sought some form of support for a psychological or emotional problem in the preceding 12 months and a further seven individuals (3%) reported that they had thought they might need to seek help from a health professional during this time (without doing so). Among those who did seek help, informal sources of support were the most common. These were reported by 70 subjects (34%). Participants most often spoke with friends (*n* = 51, 25%) and/or family members (*n* = 42, 21%). Meanwhile 20 participants (10%)

specified that they spoke to their partner, although others may have included this within friends or family. Around a third of those who sought help been in contact with professional (clinical) sources of support, generally receiving help from either a therapist or counsellor (*n* = 15, 8%) or a GP (*n* = 14, 7%). In total, 26 subjects (13%) engaged in professional help-seeking, while 52 subjects (26%) sought help from informal sources only.



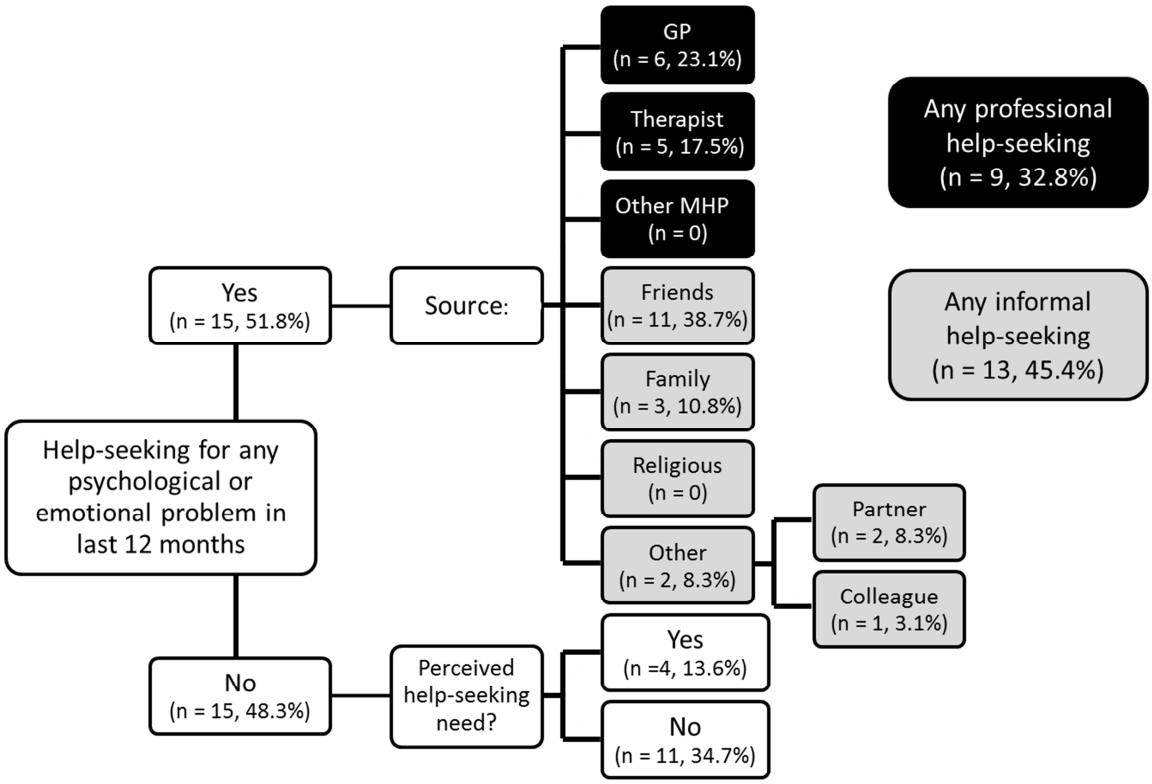
Note: Percentages are weighted. Shaded boxes may not add to 100% because of multiple responses. 'Therapist' includes any psychological therapist or counsellor, MHP = Mental health professional, 'Religious' includes any religious or spiritual leader.

Figure 9.2 Help-seeking behaviour in the full sample (*N* = 208)

Help-seeking in the UHR group

The same help-seeking questions were then examined specifically for the subgroup that met UHR criteria. Of these 30 subjects, 15 (52%) had sought help for a psychological or emotional problem in the preceding 12 months (see Figure 9.3). Moreover, nine individuals (33%) had been in touch with clinical services, of which five subjects (18%) had engaged with a service that was mental-health specific. Thirteen members of the subgroup (45%) had sought help from an informal source in the preceding 12 months and again this was most commonly from friends (*n* = 11, 39%). No individuals in the UHR subgroup sought help from a religious or spiritual leader in relation to psychological or emotional problems. In total, six subjects (19%) sought help from informal sources only. In addition to those seeking help, four individuals

(14%) perceived a need for care but were not in contact with services (explored in more detail below). The remaining eleven participants in this subgroup (35%) perceived no need to seek professional help.



Note: See Figure 9.2

Figure 9.3 Help-seeking behaviour among those meeting UHR criteria (*N* = 30)

Associations between UHR status and the odds of seeking help are shown in Table 9.3. Results of the multinomial logistic regression indicated that UHR status was associated with professional help-seeking, which remained statistically significant after adjustment for age, sex and ethnicity: OR = 5.28, 95% CI: 1.71 to 16.33. UHR status also distinguished between seeking help from different sources, in that those who met UHR criteria had over four times greater odds of seeking help from professional sources rather than informal sources only: OR = 4.62, 95% CI: 1.38 to 15.40. An additional model indicated that this may again have been explained by general psychopathology: OR = 2.79, 95% CI: 0.59 to 13.24. Nevertheless, the confidence intervals were wide for each off these findings, indicating a lack of precision.

Table 9.3 Associations between UHR status and help-seeking (*N* = 208)

		Model I (unadjusted)			Model II (adjusted)[a]			Model III (adjusted)[b]		
Comparison	*n*	OR	95% CI	*p*	Adj OR	95% CI	*p*[c]	Adj OR	95% CI	*p*
Informal help-seeking only v no help-seeking	182	0.94	0.34-2.65	.910	1.06	0.36-3.15	.917	0.40	0.09-1.91	.251
Professional help-seeking v no help-seeking	156	4.35	1.59-11.87	.004	5.28	1.71-16.33	.012	1.13	0.23-5.58	.885
Professional help-seeking v informal help-seeking only	78	4.62	1.38-15.40	.013	4.99	1.39-17.87	.028	2.79	0.59-13.24	.196

[a] Adjusted for age, sex, ethnicity [b] Adjusted for age, sex, ethnicity and general psychopathology [c] Adjusted for multiple comparisons

Note: Reference group is all those who do not meet UHR criteria.

9.3.3 Do individual characteristics predict help-seeking behaviour?

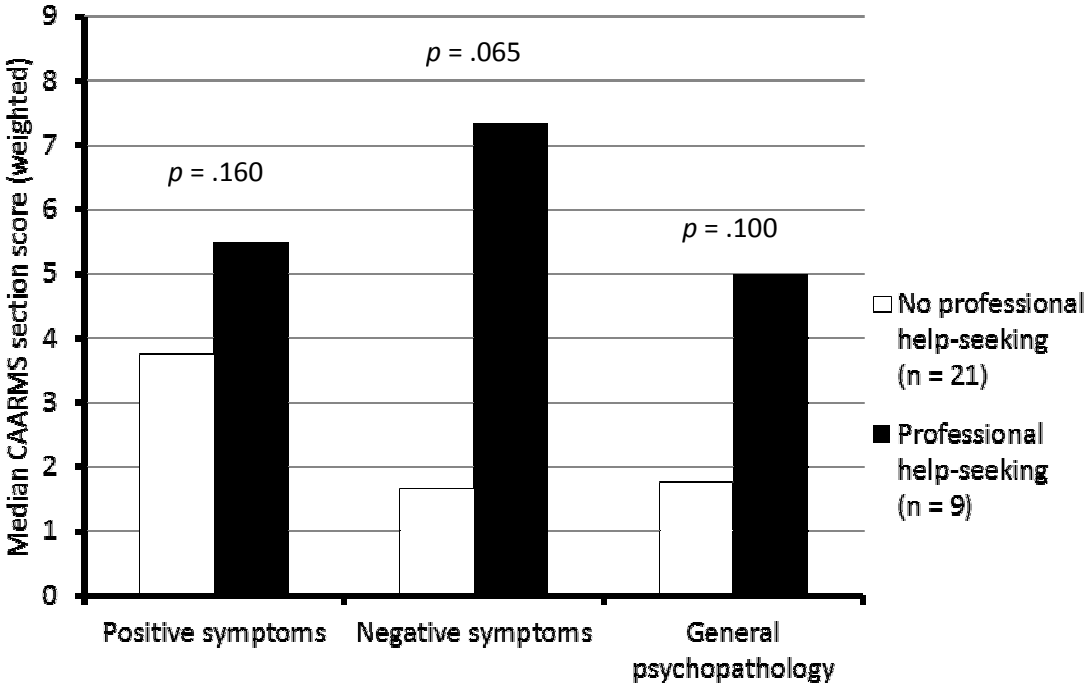
Within the UHR subgroup, professional help-seeking was examined in relation to a number of demographic variables to identify where any characteristic differences were apparent between those who sought professional help and those who did not. The pattern of professional help-seeking in relation to demographic characteristics is shown in Table 9.4. Of the 30 individuals who met UHR criteria, nine (33%) engaged in professional help-seeking, so if there was no association with demographic characteristics one would expect proportions within each demographic stratum not to deviate greatly from this.

Table 9.4 Demographic characteristics and professional help-seeking in the UHR subgroup

	Total	Help-seeking	Unweighted	*Weighted*	
	N	*n*	(%)	*(%)*	*p* †
Sex					
Male	7	1	(14.3%)	*(11.8%)*	.393
Female	23	8	(34.8%)	*(39.2%)*	
Age (years)					
18-26	20	4	(20.0%)	*(19.9%)*	.115
27-35	10	5	(50.0%)	*(58.9%)*	
Ethnic minority					
No	6	1	(16.7%)	*(16.3%)*	.637
Yes	24	8	(33.3%)	*(37.4%)*	
First generation migrant					
No	18	2	(11.1%)	*(11.5%)*	.013
Yes	12	7	(58.3%)	*(59.1%)*	
Years in education					
15 or less	14	4	(28.6%)	*(29.1%)*	.596
16 or more	16	5	(31.3%)	*(36.0%)*	
Family history of mental disorder					
No	14	3	(21.4%)	*(20.6%)*	.290
Yes	16	6	(37.5%)	*(42.5%)*	

† Exact *p* values calculated using unweighted data.

The largest difference in the sample appeared to be for migrancy. Contrary to my hypothesis, first generation migrants were significantly more likely to engage in professional help-seeking than non-migrants, with seven out of twelve migrants (59%) having spoken with a health professional about a psychological problem in the preceding 12 months, whereas only two out of eighteen (12%) of UK-born subjects had done so: $p = .013$. Non-significant trends suggested that older subjects may be more likely to seek professional help than younger subjects and that women may seek more professional help than men, although the sample size was too small to make reliable inferences. There was no evidence for any of the predicted associations with ethnicity, education or family mental disorder, even at trend level.



Note: section scores standardised for comparability. Maximum score is 36.

All *p* values corrected for multiple comparisons.

Figure 9.4 Median CAARMS section scores and professional help-seeking in the UHR subgroup (*N* = 30)

Clinical differences were also examined between those who sought professional help and those who did not. In terms of functioning, those who sought professional help generally had significantly lower GAF-S scores ($M = 61.2$, $SD = 7.76$) than those who did not ($M = 70.3$, $SD = 8.56$): $t(27) = -2.59$, $p = .030$, $r = .446$ (corrected for multiple testing). However, there was no observable difference in GAF-F scores (professional help-seeking group: $M = 69.4$, $SD = 8.19$; no professional help-seeking: $M = 70.9$, $SD = 12.98$): $t(27) = -0.39$, $p = .700$. Similarly, the CAARMS section scores examined were all higher among the professional help-seeking

group (see Figure 9.4), indicating that those who sought help tended to be more symptomatic, particularly in terms of negative symptoms. Nevertheless the statistical significance of these trends was not strong enough to survive corrections for multiple testing [positive: z = -1.41, p = .160; negative: z = -1.96, p = .100; general psychopathology: z = -2.30, p = .065], suggesting that the present sample was not sufficiently powered to explore this association.

9.3.4 Do symptom characteristics predict help-seeking behaviour?

Symptom-specific help-seeking was examined to explore what kinds of symptoms in particular led individuals to seek help in the preceding 3 months. Help-seeking for positive symptoms, basic symptoms, negative symptoms and general psychopathology are shown in Table 9.5. Despite being the least commonly endorsed, negative symptoms were proportionally the largest reason for help-seeking, with 13 (75%) of those who reported a negative symptom seeking some form of help in the preceding 3 months. General psychopathology was the most commonly experienced, with all UHR individuals endorsing at least one symptom, and 21 (70%) of those reporting general psychopathology had sought some form of help for it. For positive symptoms this was slightly lower, but still 15 (52%) of those experiencing a positive symptom in the past 3 months had sought help for it, whereas the lowest proportion of help-seeking among UHR subjects was for basic symptoms, with only nine (32%) of those who endorsed an item on the SPIA-9 seeking any form of help for it.

Table 9.5 Symptom-specific help-seeking of UHR individuals during the past 3 months (*N* = 30)

		Help-seeking for given symptom	
Symptom (to any degree)	Reported by (total *n*)	Any *n* (%)	Professional *n* (%)
Positive symptoms	28	15 (51.9%)	5 (16.6%)
Basic symptoms	27	9 (32.4%)	1 (4.0%)
Negative symptoms	17	13 (75.2%)	5 (31.0%)
General psychopathology	30	21 (70.4%)	6 (20.5%)

Note: 'Any' includes both professional and informal sources (see Figure 9.2)
All percentages are weighted.

The same trend was present when professional help-seeking was examined in isolation. Five individuals (31%) reporting a negative symptom had specifically spoken to a health professional about it in the preceding 3 months, six individuals (21%) had sought professional help for general psychopathology, five (17%) had sought help for positive symptoms and only

one individual (4%) contacted a health professional in relation to basic symptoms. Nevertheless, this may be explained by the average level of distress reported for these symptoms (shown in Figure 9.5 and in Table 9.1), which followed the same incremental pattern as just described for help-seeking.

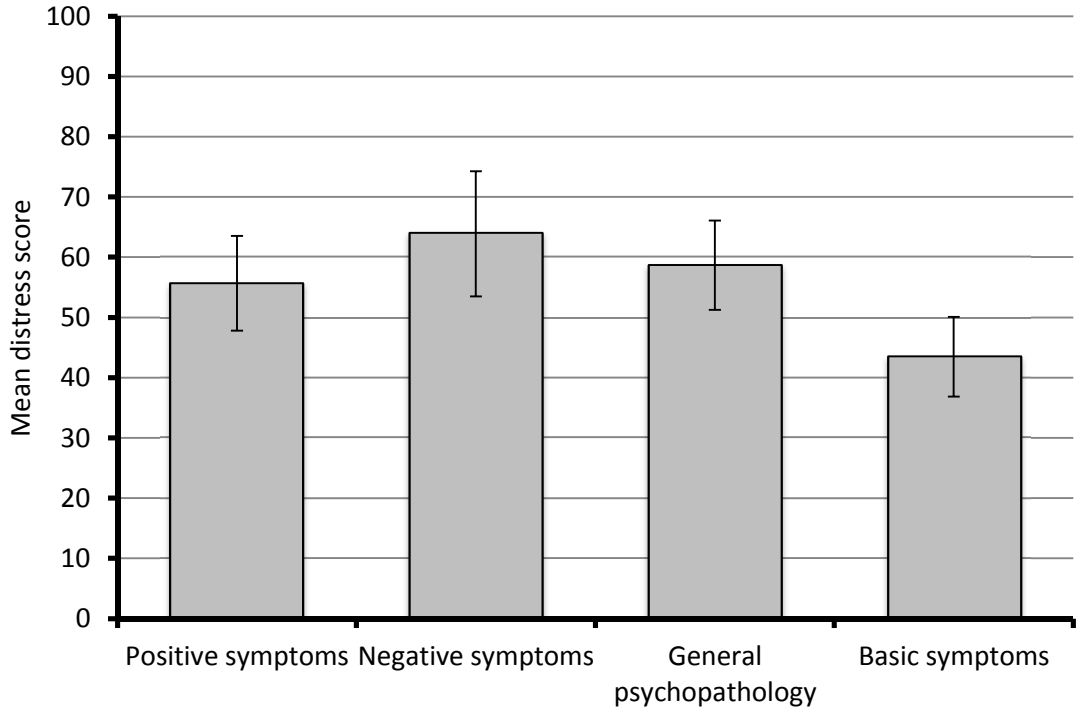


Figure 9.5 Mean distress score and symptom type within the UHR subgroup (*N* = 30)

The association between symptom type and symptom-specific help-seeking was also examined descriptively at the symptom level, that is, whether each specific symptom reported elicited a professional help-seeking response. The distribution of symptom-specific help-seeking across the symptom categories is shown in Table 9.6. Comparing this with Table 9.5 highlights that the five individuals who sought professional help for positive symptoms did so on the basis of one symptom each, while the remaining 47 positive symptoms reported (91%) did not elicit a professional help-seeking response. Likewise, this was true for 70 out of 71 basic symptoms (99%). Symptoms of general psychopathology were reported the most frequently and 13 out of 65 symptoms reported (18%) elicited a professional help-seeking response. Since six individuals reported professional help-seeking for general psychopathology (Table 9.5), this is more than two symptoms each on average.

In order to assess the direct association between distress and professional help-seeking in the UHR group, relationships between the characteristics of a given symptom and the likelihood of seeking professional help specifically for that symptom were examined across all

symptoms reported on the CAARMS and SPIA-9. Distress scores were missing for 11 symptoms, leaving a total of 327 symptoms available for analysis.

Table 9.6 Symptom-specific help-seeking for all symptoms reported within the UHR subgroup (*N* = 336)

		No professional help-seeking		Professional help-seeking	
Symptom category	Total *(n)*	*n*	(%)	*n*	(%)
Positive symptoms	54	49	(91.4%)	5	(8.6%)
Cognitive change	25	20	(80.3%)	5	(19.8%)
Emotional disturb	8	5	(62.8%)	3	(37.2%)
Negative symptoms	29	22	(74.0%)	7	(26.0%)
Behavioural change	45	40	(87.7%)	5	(12.3%)
Physical change	26	22	(84.0%)	4	(16.0%)
General psychopathology	78	65	(82.1%)	13	(18.0%)
Basic Symptoms	71	70	(98.5%)	1	(1.5%)
Total	**336**	**293**	**(86.7%)**	**43**	**(13.3%)**

Note: this table refers to individual symptoms not individual subjects

This symptom-level analysis revealed a significant association between subjective distress and professional help-seeking, while accounting for the clustering of symptoms within each individual (see Table 9.7). The unadjusted comparison revealed that the symptoms which caused a high level of distress were associated with a fivefold increased odds of professional help-seeking, compared with those which caused only a low level of distress: OR = 5.19, 95% CI: 2.01 to 13.41. Adjusting for the symptom category (*c.f.* Table 9.6) indicated that the association between symptom distress and specific help-seeking existed independently of the symptom form and was only slightly weakened by the adjustment: OR = 4.53, 95% CI: 1.61 to 12.70. This association appeared to be largely explained by symptom severity as the association with subjective distress was no longer significant when the severity score was entered into the model: OR = 2.13, 95% CI: 0.63 to 7.21. However, symptom type did contribute significantly to the predictive power of the final model: Wald $\chi^2(7) = 46.15$, $p < .001$. The model itself (Table 9.7, Model III) was highly statistically significant [Wald $\chi^2(10) = 85.96$, $p < .001$] but had a modest effect size [Tjur's $D = .168$], indicating that other important predictors were not included.

Table 9.7 Association between symptom distress and professional help-seeking for that symptom: an analysis of all symptoms reported within the UHR subgroup (*N* = 327)

		Model I (unadjusted)			Model II (adjusted)[a]			Model III (adjusted)[b]		
Subjective distress level	*n*	OR	(95% CI)	*p*[c]	Adj OR	(95% CI)	*p*[c]	Adj OR	(95% CI)	*p*
Low (0-32)	182	1.00	--	--	1.00	--	--	1.00	--	--
Medium (33-65)	156	2.18	(0.66-7.16)	.200	2.26	(0.61-8.40)	.224	1.57	(0.44-5.57)	.483
High (66-100)	78	5.19	(2.01-13.41)	.002	4.53	(1.61-12.70)	.008	2.13	(0.63-7.21)	.225

[a] Adjusted for symptom type [b] Adjusted for symptom type and symptom severity [c] Adjusted for multiple comparisons

Note: Reference group is no professional help-seeking. 95% confidence intervals based on cluster-correlated robust standard errors.

9.3.5 Why might UHR individuals not seek help?

Four individuals were identified within the UHR subgroup who perceived a need for care in the previous 12 months but had not sought professional help (Figure 9.3). The demographic and symptomatic profiles of these individuals were inspected and data about their reasons for not seeking help and their attitudes towards health services in general were examined qualitatively. Names used are pseudonyms.

Table 9.8 Demographic and clinical profile of non-help-seekers

Demographic profile	Ella	Cherry	Harriet	James
Age	24 years	27 years	19 years	24 years
Sex	Female	Female	Female	Male
Ethnicity	Black African	Black Caribbean	White British	Black Other
Work status	Employed	Employed	Unemployed	Student
Education level (years in education)	University (17 years)	University (19 years)	School (12 years)	University (18 years)
Family history of mental illness	None	None	Psychosis and depression (Mother)	None
Clinical profile				
UHR subgroup	BS	BS	GRD	BS
ANS criteria	No	No	No	Yes
Functional change	Mild decline	None	Marked decline	Marked decline
GAF-S	63	75	58	62
GAF-F	75	88	51	51

BS = Basic Symptom, GRD = Genetic risk and decline, ANS = Attenuated negative symptoms

Note: All names are pseudonyms.

Demographic and clinical profiles

Demographic and clinical profiles are shown in Table 9.8. The four individuals identified were all from the younger half of the study's age range (19-27 years) and tended to be female, in proportion with the make-up of the UHR subgroup. Three of the four were demographically

very similar - Black (although each reported a different ethnicity), no family history of mental illness, highly educated and currently in full time study or employment – and all met Basic Symptom criteria. In contrast, the other was younger, white, unemployed, less well educated, reported a family history of mental illness including psychosis, and met PACE criteria for a genetic risk and decline. Interestingly, none of these individuals met UHR criteria for attenuated positive symptoms despite this being the most common reason for meeting UHR criteria. Finally, perceived functional change and current GAF scores indicated variation in functional impairment. While all four experienced relatively similar levels of psychological functioning (GAF-S), social and occupational functioning was much lower for Harriet (by definition) and for James, who was the only one to also meet criteria for attenuated negative symptoms.

Specific reasons and attitudes

All four individuals endorsed multiple reasons for not seeking help but the specific reasons given and attitudes behind them were varied. All four non-help-seeking UHR subjects gave reasons which implied a lack of understanding or awareness of services that were available, such as associating the GP with physical problems and not emotional ones, and expressed either a preference to deal with things on their own or a belief that things would resolve on their own without additional help. Personal concerns, such as not feeling comfortable seeing a doctor, were also commonly given as reasons. Attitudes towards the use of health services were usually consistent with reasons for not seeking help. For example Cherry mainly cited practical barriers to seeking help, such as lack of time, and had the most positive view of health services of the four, believing that 80% of individuals receiving professional treatment would benefit from it. In contrast, Harriet alone endorsed a number of negative views about the health services, for example not trusting the doctor, and expressed the lowest view of health services, believing that only 50% of those seen would benefit. James was alone in believing that he would probably not feel comfortable talking about personal problems with a professional and would feel embarrassed if his friends knew about it. Interestingly, none of these individuals endorsed concerns that people might pass judgement on them for having these problems.

9.4 Discussion

The first aim of the present chapter was to establish whether meeting UHR criteria in the community was associated with distress, impairment and a need for care. Results presented here indicate that those who meet UHR criteria report significantly more distress, poorer functioning and a greater need for care than those who do not meet criteria. In particular,

around two thirds of these individuals subjectively reported an unmet need. The second aim was to investigate what proportion of the community UHR group was currently engaged in help-seeking and to explore what personal and symptomatic features might predict this help-seeking behaviour. The main finding was that around two thirds of the UHR group had either recognised a help-seeking need or actively sought help. Moreover, individuals who met UHR criteria were over four times as likely to seek professional help as those who did not meet criteria, with one third of the UHR group already engaged with professional health services. Help-seeking behaviour appeared to be largely a function of more distressing and more severe symptoms, although subjects were less likely to seek help for basic symptoms than for general psychopathology or negative symptoms. Finally, there was little evidence that demographic features predicted help-seeking behaviour. However, against my prediction, first generation migrants were more likely to seek help than those born in the UK.

Carefree or need for care?

Assessing the level of distress, dysfunction and need for care associated with the UHR criteria is important for understanding how meaningful it is to identify this group in the general population. In general, the findings suggest that the community UHR group does appear to show some degree of need for care compared to the rest of the sample, broadly supporting my first hypothesis. Regardless of which UHR criteria were met, all individuals in the UHR group reported some degree of general psychopathology, while positive symptoms and basic symptoms were each reported by 28 out of the 30 individuals (94%). This indicates that even in an unselected community sample, the UHR criteria tend to identify individuals who are experiencing a range of symptomology. This is in line with findings from clinical samples (Fusar-Poli et al., 2014a). The UHR subjects did appear to be relatively distressed by their experiences, compared with others who reported symptoms but did not meet criteria. Similarly, the UHR group exhibited lower functioning, lower IQ and were more likely to report an unmet need than those who did not meet UHR criteria. In line with findings from Simon et al. (2007), the BS criteria subgroup appeared to be slightly less impaired than the PACE subgroup, although this difference was not significant and no difference was observed in relation to need for care between the subgroups.

Nevertheless, it is important to consider these findings critically. CAARMS distress ratings are entirely subjective and, as this study is the first to apply the distress scale to all symptoms, no comparison data are available from other studies. Therefore it is difficult to interpret the level of distress in absolute terms, particularly when taken as an average. However, these ratings do demonstrate relative differences in distress between different kinds of symptoms.

In particular, basic symptoms appear to be less distressing and negative symptoms most distressing among the UHR group. Although global functioning scores were lower in the UHR group than the rest of the population, the difference was relatively small. GAF scores of 68 and 70 are also substantially higher than those previously reported for clinical UHR patients (Mean = 58; Fusar-Poli et al., 2010). Nevertheless, a GAF score of below 70 has been used by some authors to define an impairment in functioning (McGorry and Goldstone, 2011). On this basis, 10 of these UHR subjects (33%) would be considered to have a functional impairment (according to GAF-F scores, not shown). Unmet needs scores in the UHR group were close to a previous study of patients with established psychosis and affective disorder (van der Krieke et al., 2011). About 66% of UHR subjects reported an unmet need. These findings do seem to indicate that the UHR criteria are measuring something clinically meaningful in the community.

The pattern of help-seeking also supports this interpretation. In total, close to two thirds (65%) of the community UHR sample had at least perceived a need to seek help for a psychological or emotional problem in the previous 12 months. Moreover, about half (52%) had already engaged in some form of help-seeking during this time. Friends were the most common source of help-seeking, while half of the UHR group (50%) had spoken with either friends or family, which echoes findings elsewhere for a number of mental health problems (Reavley et al., 2011). This is potentially indicative of an initial recognition that there is a problem, since it has been shown elsewhere that close friends and family are often the first help-seeking contact that people make on the pathway to care in early psychosis (Fridgen et al., 2013). In line with expectations, those who met UHR criteria were also significantly more likely to seek professional help than those who did not. Around one third (33%) of the UHR group had sought professional help in the last year, far higher than the 5% or less who had demonstrated help-seeking behaviour in previous community UHR studies (Kelleher et al., 2012d; Zammit et al., 2013). Most of these help-seeking individuals had been in contact with their GP but more than half had (often additionally) seen a counsellor or psychological therapist. Given that none of these individuals had currently been in contact with specialist UHR services, one possibility is that these individuals were already receiving adequate support from current sources. This could be explained by the community UHR group either being less symptomatic and less functionally impaired than patient groups, or by them having a greater level of social support available, which has been shown to reduce the use of specialist psychiatric services (Maulik et al., 2009). However, it is pertinent that more than half of the delay in reaching specialist UHR services has been found to occur within the health service itself rather than prior to the first help-seeking contact (von Reventlow et al., 2014), which also raises the possibility that there may be a lack of education about the recognition of UHR

individuals and a lack of awareness about when or where to refer them for specialist clinical care. This may be particularly true of those who present without the positive symptoms that have traditionally been prioritised and are objectively most recognisable. Nevertheless, it is also important to note that around 35% of the sample did not recognise a help-seeking need, suggesting either that their symptoms were not problematic, or alternatively that there may have been a lack of insight into the problematic nature of these symptoms or a lack of awareness that help was available.

What drives help-seeking?

My remaining hypotheses were in relation to what predicted help-seeking behaviour. The findings generally suggested that help-seeking was more related to differences in symptoms than to other individual differences. The evidence did not support any of my predictions with regards to demographic variables or family history, although this may have been partly related to the small sample size. The only clear finding was that first generation migrants, contrary to my prediction, were more likely to seek professional help than those born in the UK. This is surprising given findings that Black Africans (80% of whom were first generation migrants) may be less willing to speak to their GP about emotional problems (Maginn et al., 2004). However, the first generation migrant group in this sample were highly heterogeneous (eleven different nationalities, of which six were European), which may explain why the same patterns have not been observed. Moreover, it is plausible that migrants would be particularly likely to make use of health services since free NHS healthcare is one of the UK's most attractive features. Nevertheless, this finding should be interpreted cautiously given the small sample.

Stronger associations were demonstrated in relation to clinical features. In general, help-seeking within the UHR group was associated with lower psychological functioning (in other words a higher global symptom level), although not with social and occupational functioning. These individuals also appeared to show more concurrent negative symptoms and general psychopathology than non-help-seekers, perhaps in line with an accumulation of distress (Fusar-Poli et al., 2014b), although this was only present at trend level. Nonetheless, help-seeking members of the UHR group appeared to be experiencing higher levels of symptoms but were no more impaired in their daily lives than those who did not seek help. This could suggest that impaired social and occupation functioning is not something that leads to help-seeking in this group, perhaps because impairment is not as severe as in clinical samples (as discussed above). Alternatively, given that the temporal nature of these events is not known, it is possible that seeking professional help has enabled these individuals to cope better with

their symptoms, such that they do not impact on their daily lives. This explanation would be consistent with UHR individuals receiving adequate care from non-specialist services.

In terms of symptoms themselves, descriptive findings at the person level appeared to be in line with the findings related to distress. In line with my predictions, individuals were least likely to seek help for basic symptoms, which were also regarded as the least distressing, and more likely to seek help for negative symptoms and general psychopathology than specifically for positive symptoms, which fits with findings elsewhere (Kobayashi et al., 2011; Schultze-Lutter et al., 2013a). It is important to highlight that UHR subjects were most likely to seek help for negative symptoms. This is plausible, since negative symptoms may be harder for the individual to cope with, and may in fact impair their coping abilities (Mäkinen et al., 2008), triggering a need for external support. Along with affective symptoms, negative symptoms have been associated with more social impairment, psychological functioning and poorer quality of life among the clinical UHR group (Demjaha et al., 2012; Domínguez-Martínez et al., 2013). Negative symptoms may be subjectively recognised by UHR individuals because of comparatively higher levels of insight in this group than in patient groups (see Lappin et al., 2007). Given that negative symptoms may be burdensome, associated with poorer outcomes and do not respond well to treatment (Mäkinen et al., 2008), the ability to identify them at a point where there is more insight could possibly represent an opportunity to improve treatment success. Nevertheless, because of the small sample size the associations between particular symptoms and help-seeking could not confidently be inferred to be true for the population. To account for this, analyses were also conducted at the symptom level, making use of all 327 symptoms reported by the 30 UHR individuals. These findings indicated that help-seeking was predicted more by the distress associated with a symptom than by the symptom type. In turn, this association was explained by the symptom severity. Together these findings suggest that basic symptoms may be generally experienced at the least severe levels, and thus be less distressing and less likely to elicit a help-seeking response, whereas the reverse is true of negative symptoms, general psychopathology and, to a lesser extent, positive symptoms.

Finally, the qualitative exploration of individuals who perceived a need for help revealed a range of reasons expressed for this, hinting at personal and practical barriers to care. However, there were far too few individuals to make reliable inferences about this group. Nonetheless it was interesting to note that none of these individuals met APS criteria, despite this being most commonly identified group. One way of explaining this is that the APS group is typically also associated with high levels of general psychopathology and also negative symptoms, which

have been highlighted as important reasons for seeking help both here and in the wider literature (e.g. Schultze-Lutter et al., 2013a).

Limitations

The findings presented in this chapter are subject to a number of limitations. The most important of these is the small sample size available, particularly when examining help-seeking and non-help-seeking trends within the UHR group. This restricted both the analyses that could be conducted and the associations that could be detected. This issue is discussed in more detail in Chapter 11 (p.171). The novelty of these findings makes them a useful starting point. However, replication in a larger sample is certainly warranted. Other limitations relate to what can and cannot be interpreted from the specific measures used. For example, information about distress was completely subjective and the 0-100 scale contained no particular guide. It is therefore difficult to make comparisons between individuals. However, as I have mentioned above, it is useful for demonstrating relative differences between types of symptoms. In a similar vein, the use of the general psychopathology score from the CAARMS is useful for providing a dimension of common mental disorder, but is less comparable to other research. The inclusion of a clinical measure to indicate the presence of diagnosable mental disorders would have helped enabled better comparisons with clinical studies.

A key strength of this study has been the examination of help-seeking behaviour in relation to specific symptoms, providing an insight into the types of symptoms that are likely to lead individuals to seek professional help. However, the data I collected do not distinguish symptoms that were the primary reason for seeking help from those for which help was sought more incidentally. For example, it is possible that an individual who is experiencing both depression and occasional hallucinations might see a counsellor for their depression and consequently may also speak to them about the hallucinations, whereas they may not have approached the counsellor on the basis of the hallucinations alone. This would be recorded as seeking help for both positive symptoms and general psychopathology. However, this conceptual distinction is important for understanding the nature of what leads to help-seeking behaviour. Similarly, the order of help-seeking contacts was not collected. This may also be important for furthering our understanding of the help-seeking process and understanding how best to target information and education about the UHR state.

Moreover, help-seeking intention was only recorded in relation to a perceived need to seek professional help. Therefore individuals who ‘did not perceive a help-seeking need’ relates to all those who had not expressed a need to seek professional help and who had not sought help from any informal source. This may therefore include individuals who perceive a

problem but have other reasons for not wanting to use health services. Unfortunately the data collected did not explore non-help-seeking reasons among those who did not recognise a problem. Given that these individuals objectively met symptomatic UHR criteria, this may be a particularly useful group for exploring either the suitability of these criteria or the nature of insight in those with UHR symptoms.

Conclusion

Taken together, the findings presented in this chapter suggest that those who meet UHR criteria in the general population are not altogether healthy. Compared with those who do not meet criteria, these individuals are more functionally impaired and more often help-seeking, supporting the notion that the UHR criteria are identifying something meaningful even in an unselected general population sample. Nevertheless, those meeting UHR criteria in the community are a heterogeneous group both symptomatically and in terms of need for care. On one hand this perhaps confirms the notion that the symptomatic criteria alone may be insufficient for identifying a clinically relevant population. On the other hand, none of these individuals would be known to services based on current criteria, and yet two thirds of this group report a need for care and over half are currently seeking help for their symptoms. Furthermore, although these community UHR group appear to be faring worse than other members of the community, there is a suggestion that they may still be higher functioning and potentially less symptomatic than those who currently present to clinical UHR services. Together these findings are consistent with the idea that a proportion of the community UHR individuals identified (perhaps around two thirds) might be considered to be of clinical relevance and may be comparable with those who present to UHR services. Whereas another proportion of these individuals (perhaps one third) may be experiencing relevant symptoms but may be relatively undisturbed by them or may have sufficient wherewithal to cope with them effectively. More research would be necessary to confirm this speculation. Most importantly, it is not known to what extent those meeting UHR criteria in the general population are representative of those currently engaged with UHR services. As Kelleher et al. (2012d) rightly observe, research comparing community and clinical samples is necessary to understand whether differences extend beyond the simple act of help-seeking.

CHAPTER 10 RESULTS (4) – A CASE OF MISTAKEN IDENTITY? COMPARISONS WITH CLINICAL HELP-SEEKING OASIS CLIENTS.

10.1 Aims and hypotheses

The previous two chapters have shown that not only do a proportion of the general population meet UHR symptom criteria, but many of them are distressed by their experiences and are help-seeking. Within this group, seeking help from clinical services was particularly associated with migrant status, negative symptoms and concurrent symptoms of common mental disorder. Nevertheless, none of these individuals had sought help from the local specialist UHR service[6], raising the question: how do they differ from people who do present to such services?

One possibility is that the two groups do not differ in terms of their experiences but rather they have simply elected to seek help from different types of agency (or not at all). Certain types of individuals might also be more likely to be referred to specialist UHR services than others, reflecting some bias on the part of the referrer. In both respects, demographic differences could play a significant role. It is also possible that subjects who are more intelligent or have greater cognitive resources may be better able to cope with symptoms and thus support received outside of specialist services may be adequate.

Alternatively, the groups may differ according to their clinical profiles. Specifically those with more severe positive, negative and general psychopathology, or whose symptoms are associated with more impaired functioning and more subjective distress, may be referred to a specialist high risk service, whereas those with less marked symptoms may instead present to other health and non-health agencies, if at all. Another possibility is that rather than quantitative differences in symptoms, clinical and community groups may be characterised by different types of symptoms. Specifically, subjects who meet UHR criteria in the community may be more likely to be characterised by basic symptoms, as opposed to attenuated positive symptoms which may be more easily recognised as being linked to psychosis.

The aim of the present chapter was to address these issues by comparing the community UHR sample with UHR subjects who presented to a specialist high risk service.,

The following hypotheses were tested:

H_1 The community UHR group will resemble the patient group in terms of demographic features.

[6] (with the exception of one individual who had since experienced a first episode of psychosis and was therefore excluded from the study)

H_2 The community UHR group will show greater cognitive ability than the clinical sample.

H_3 Compared to the clinical sample, the community UHR group will have

a. Fewer and less severe attenuated positive symptoms
b. Less severe attenuated negative symptoms
c. Less concurrent general psychopathology
d. More impaired functioning

H_4 A greater proportion of the community UHR group will meet Basic Symptom criteria alone.

10.2 Method

10.2.1 Patient sample (n=37)

Patients were recruited from Outreach and Support in South London (OASIS; Broome et al., 2005; Fusar-Poli et al., 2013c), the local specialist clinical service for UHR subjects. The patient sample was obtained from a separate research study that had recruited patients over a similar time period to the present study (between January 2011 and March 2014). The patients were assessed shortly after clinical presentation, so the measures were taken close to the time their first contact with the specialist service. The sample is broadly representative of OASIS patients in general in terms of basic demographics.

All patients in the sample met criteria for the UHR state at the time of interview. To date, five of these individuals had developed a first episode of psychosis subsequent to the assessment.

10.2.2 Measures

Individual characteristics

The two groups were compared in terms of age, sex, ethnicity, education, current employment, migrant status, cannabis use and treatment history. Because of potentially small sample sizes, ethnicity was collapsed into three groups: 'White', 'Black' and 'other'. The two studies used different batteries of cognitive assessments so there was not a directly comparable IQ measure. However, the Digit Symbol Coding subtest from the shortened WAIS was included as an indication of processing speed and number of years in education was included as a proxy for intelligence.

Clinical characteristics

The groups were compared with respect to attenuated positive symptoms, attenuated negative symptoms and general psychopathology using the CAARMS, and functional impairment using GAF scores. Nevertheless only a subset of the data was available. Global severity scores were available for all subscales of the CAARMS (0-6 scale). Overall severity scores were created by calculating the mean severity of all the subscales within each of the following sections: positive symptoms (4 subscales), negative symptoms (3 subscales) and general psychopathology (8 subscales)[7]. No comparable data were available in relation to basic symptoms. However, a single grouping variable denoted the UHR subgroup criteria met by each patient as APS, BLIPS, GRD or BS alone.

10.3 Analytic strategy

Primary comparisons were made between the group who met UHR criteria in the community (*n* = 30) and the OASIS patient group (*n* = 37). The groups are presented and compared in terms of basic demographic characteristics and current cannabis use; frequencies and proportions are presented. The significance of associations between categorical variables was assessed using chi-squared tests, reporting Cramer's phi (ϕ_c) for effect sizes, while the age difference between groups was assessed using a Mann-Whitney U test. For cognitive measures, mean processing speed scores were compared using a Student's t-test. A multiple regression analysis was performed to test the association with years in education to allow age to be held constant. Average severity scores were calculated and compared for each of the positive symptoms, negative symptoms, and general psychopathology sections of the CAARMS. Nonparametric Mann-Whitney U tests were used for group comparisons. Since UHR status relies most on positive symptoms, positive symptom subscales were examined separately to investigate more specific differences between the two samples. Functioning scores were compared using t-tests, with effect size *r* reported for significant results. Pearson's correlations were used to assess the relationship between GAF scores and symptom severity scores. Finally, the frequencies and distributions of different UHR subgroups were then examined within each sample, using a chi-squared test to assess statistical significance. Finally, based on the findings of this analysis, average symptom severity scores were examined just for those who met APS criteria in each sample, to maximise comparability.

[7] The theoretical maximum of this scale is 6, but for the positive symptoms section this would indicate full psychotic severity for all four subscales in the section.

Although contrasts were all made between community and patient UHR groups, data from participants who did not meet UHR criteria are included as a control group where this is likely to aid interpretation. Corrections were made for multiple testing as appropriate, using the Hochberg procedure, and only adjusted *p* values are reported. Reported *p* values are all two-tailed and percentages are unweighted. All analyses were conducted using Stata 11.2, other than effect sizes which were calculated using formulae in Appendix C (p.244).

10.4 Results

10.4.1 Sample characteristics

The demographic characteristics of the two samples are displayed in Table 10.1. The largest difference between the groups was in terms of migrant status. First generation migrants made up 40% (*n* = 12 of 30) of the community sample but only 11% (*n* = 4 of 36) of the patient sample (shown in Figure 10.1). This difference remained statistically significant after corrections for multiple comparisons: $X^2 = 7.44$, $p = .036$, $\phi_c = .336$.

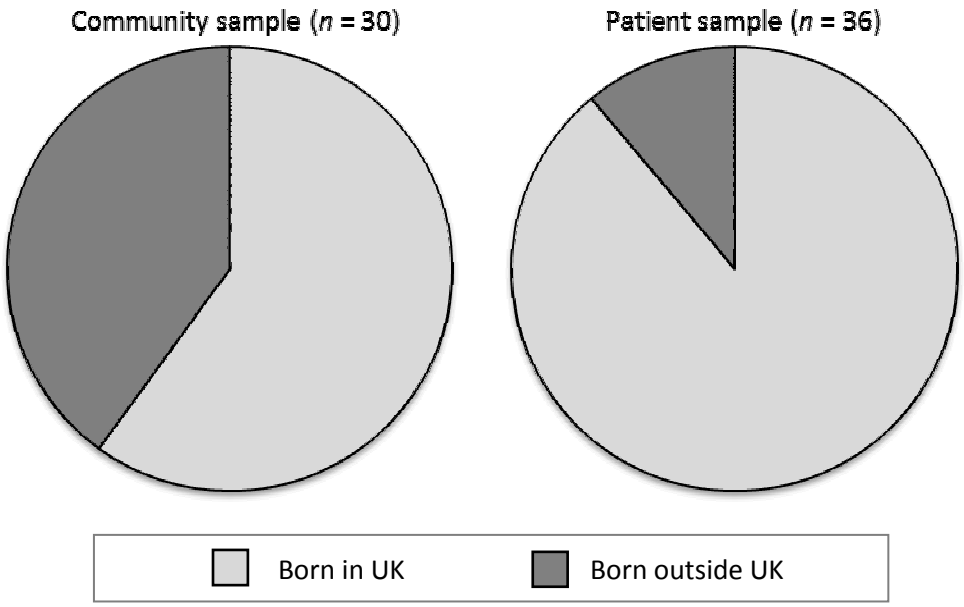


Figure 10.1 Proportion of first generation migrants: 40% v 11%, *p* = .006 (uncorrected)

Using a more liberal significance threshold, the community group appeared to be slightly older and had a much higher proportion of females than the patient group. However, these differences were not statistically significant after applying corrections for multiple testing, suggesting that a larger sample would be needed to reliably detect these differences. There was no significant difference in ethnicity, although the patient sample contained a higher proportion of individuals who were white (49% patient v 33% community). There was a higher

proportion of current cannabis users among the patients (54%) than in the community (25%) sample, but this was not significant after correcting for multiple comparisons: $p = .099$.

Table 10.1 Characteristics of the community and patient samples

	Community (n = 30)		Patient (n = 37)				
	Median	(IQR)	Median	(IQR)	z	df	p†
Age (years)	25	(22-29)	22	(21-25)	2.30	65	.084
	n	(%)	*n*	(%)	χ^2	df	p†
Sex							
Male	7	(23.3%)	20	(54.1%)	6.50	1	.055
Female	23	(76.7%)	17	(45.9%)			
Ethnicity							
White	10	(33.3%)	18	(48.7%)	2.11	2	.696
Black	15	(50.0%)	16	(43.2%)			
Other	5	(16.7%)	3	(8.1%)			
Current employment *(0 + 1 missing value)*							
Employed	12	(40.0%)	11	(30.6%)	-	-	.351‡
Economically inactive	2	(6.7%)	0	(0.0%)			
Student	9	(30.0%)	16	(44.4%)			
Unemployed	7	(23.3%)	9	(25.0%)			
Migrant status *(0 + 1 missing value)*							
Born in UK	18	(60.0%)	32	(88.9%)	7.44	1	.036
Born outside UK	12	(40.0%)	4	(11.1%)			
Current cannabis use *(2 + 13 missing values)*							
No	21	(75.0%)	10	(45.5%)	4.56	1	.099
Yes	7	(25.0%)	12	(54.5%)			

† p values adjusted for multiple comparisons

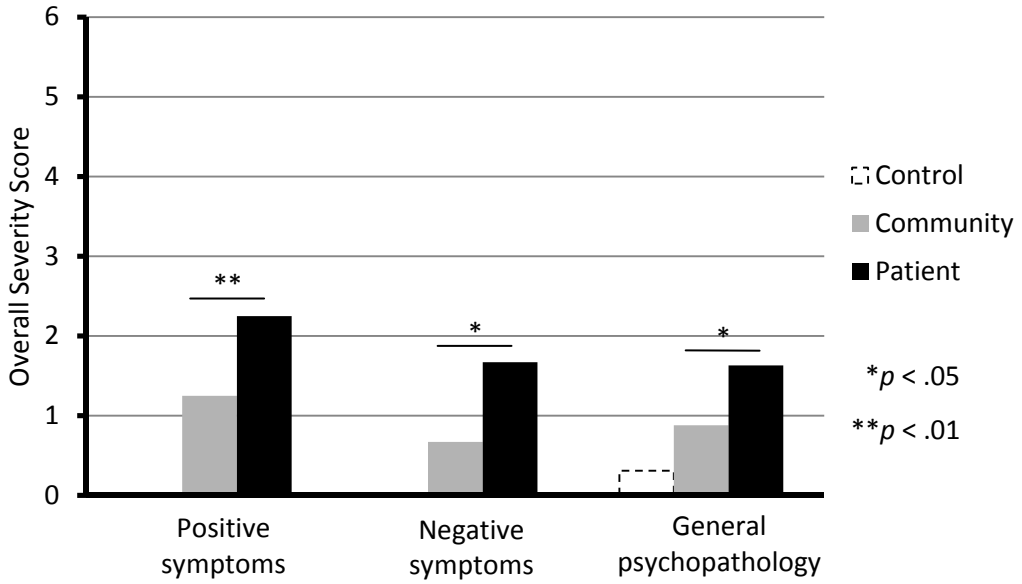
‡ Fisher's exact p value (two-tailed)

10.4.2 Cognitive ability

No significant group differences were observed in relation to processing speed [M (SD): community = 67.1 (14.9), patient = 72.3 (15.5); $t(64) = -1.38$, $p = .173$] or in the number of years spent in education: community = 15.4 (3.34), patient = 14.4 (1.90); $\beta = -0.51$, $t(62) = -0.76$, $p = .448$ (adjusted for age).

10.4.3 Symptom severity and functional impairment

Overall symptom contrasts between the samples are shown in Figure 10.2. The clinical group had more severe ratings than the community sample across all of the types of symptoms tested. The strongest difference was in positive symptoms, with severity scores (scale max = 6) significantly higher in the clinical (*Mdn* = 2.25, IQR = 1.50 to 3.25) than in the community group (*Mdn* = 1.25, IQR = 0.75 to 1.75): $z = -4.21$, $p < .001$, $r = .515$. Likewise, there was evidence for significantly more severe negative symptoms [*Mdn* (IQR): community = 0.67 (0.00 to 1.67), patient = 1.67 (0.67 to 3.00); $z = -2.63$, $p = .017$, $r = .321$] and significantly more severe general psychopathology scores in the patient group: community = 0.88 (0.50 to 1.13), patient = 1.63 (0.63 to 2.25); $z = -2.74$, $p = .019$, $r = .334$.



Note: *p* values adjusted for multiple comparisons

Figure 10.2 Median severity scores for CAARMS sections (control bar included for comparison)

Positive symptom subscales were then examined in isolation, the results of which are shown in Table 10.2. Again, the patient group scored more highly than the community group on all subscales, with the strongest differences for unusual thought content [$z = -3.71$, $p = .001$] and non-bizarre ideas [$z = -3.51$, $p = .002$], both of which achieved a moderately strong effect size: $r = .454$ and $r = .428$ respectively. The patient group also endorsed significantly more positive symptoms (*Mdn* = 2, IQR = 1-3) than the community UHR group (*Mdn* = 1, IQR = 0-2): $z = -3.58$, $p < .001$, $r = .438$.

Table 10.2 Median severity scores for CAARMS positive symptom subscales, by UHR sample

	Community		Patient			
	Mdn	(IQR)	Mdn	(IQR)	*z*	*p*†
Unusual thought content	0	(0-0)	3	(0-4)	-3.71	.001
Non-bizarre ideas	1	(0-3)	3	(2-4)	-3.51	.002
Perceptual abnormalities	2	(0-3)	3	(0-4)	-1.59	.111
Disorganised speech	0	(0-2)	2	(0-2)	-1.71	.176

† *p* values adjusted for multiple comparisons

Mean general functioning scores of community and patient groups are shown in Figure 10.3, along with the scores of the control group (included for visual reference only). The patient group had lower GAF-S scores (M = 56.3, SD = 9.40) than the community group (M = 68.1, SD = 9.32), which was highly statistically significant [$t(63) = 5.03$, $p < .001$] and carried a large effect size: r = .536. The same pattern was present for GAF-F scores with mean scores of 60.9 (SD = 11.25) in the patient group and 70.3 (SD = 11.74) in the community, and was again statistically significant [$t(63) = 3.30$, p = .003] and represented a moderate effect: r = .384.

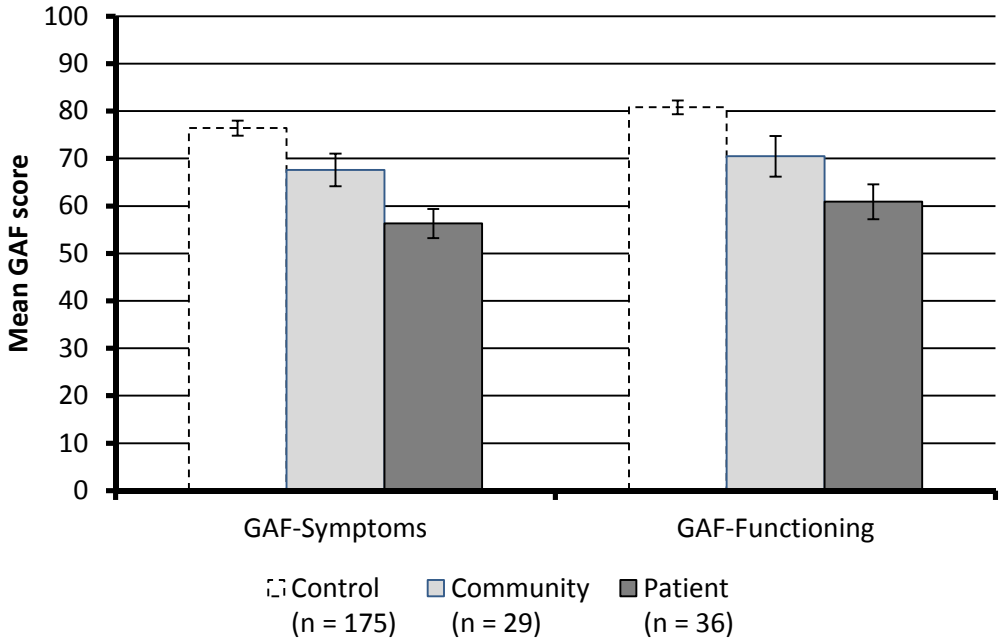


Figure 10.3 Functional impairment across UHR groups (controls included for visual comparison)

Correlations between symptom severity and functional impairment within each sample are shown in Table 10.3. Interestingly, the patterns of association differed between the two

samples. In the community sample, all three symptom types were strongly correlated with GAF-S scores, but only positive symptoms were associated with GAF-F scores. In contrast all three symptom types showed a moderate negative correlation with GAF-F scores in the patient group, but none were associated with GAF-S.

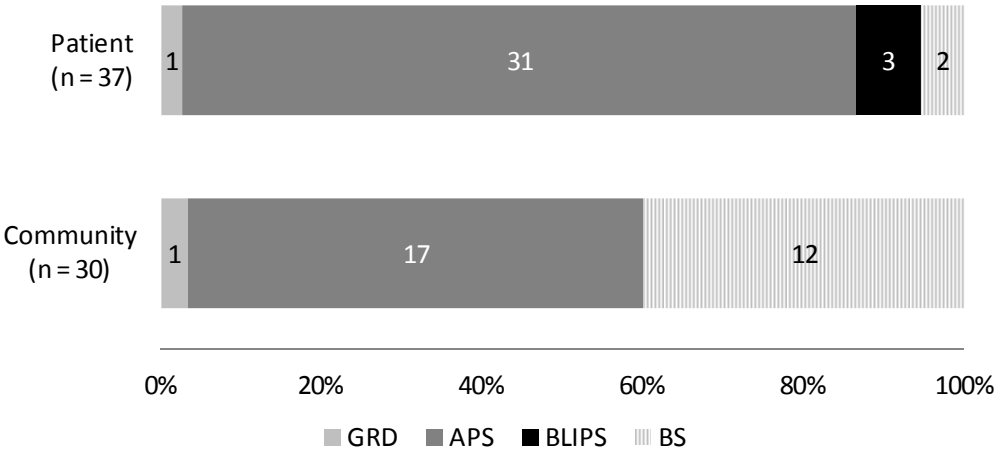
Table 10.3 Correlation between symptom severity and global functioning

	Community (*n* = 29)		Patient (*n* = 36)	
Symptom type	GAF-S	GAF-F	GAF-S	GAF-F
Positive symptoms	**-.535****	**-.541****	-.342	**-.341***
Negative symptoms	**-.499****	-.126	-.236	**-.472****
General psychopathology	**-.624*****	-.394	-.305	**-.460****

*p < .05 **p < .01 ***p < .001 (adjusted for multiple comparisons)

10.4.4 Symptomatic profile: examining the inclusion criteria

The distribution of different UHR subgroups within each sample is shown in Figure 10.4. The majority of individuals in each sample primarily met APS criteria; however, the proportion that did so was greater among the patient sample (84%) than in the community sample (57%). Three individuals met BLIPS criteria in the patient group (8%) compared with none of the community sample. On the other hand the proportion of subjects who met BS criteria alone was greater in the community UHR sample (40%) than in the patient sample (5%). Taken together, these differences were shown to be statistically significant [$\chi^2(3) = 13.64$, $p = .003$] with a moderate effect size: $\phi_c = .451$.



Note: Where individuals met criteria for two groups, BLIPS >APS > GRD > BS

Figure 10.4 Proportion and frequencies of different UHR criteria groups

Finally, it was noted that the differences in symptom severity shown above were confounded by the differences in clinical profile between the two samples. Therefore to parse out the impact of more individuals in the community sample meeting BS criteria, overall symptom comparisons were repeated just for participants in each sample who met APS criteria. The results of this are displayed in Table 10.4.

Table 10.4 Median severity scores for CAARMS sections: comparing just the APS subgroups

	Community (*n* = 17)		Patient (*n* = 31)			
	Mdn	(IQR)	Mdn	(IQR)	z	p†
Positive symptoms	1.75	(1.50-2.00)	2.25	(1.50-3.50)	-2.35	.018
Negative symptoms	0.67	(0.00-1.67)	1.67	(0.67-3.00)	-2.04	.042
General psychopathology	0.88	(0.63-1.63)	1.88	(0.75-2.50)	-2.30	.021

† *p* values adjusted for multiple comparisons

Even between these comparable subgroups, patients meeting APS criteria scored more highly than their community counterparts for negative symptoms (z = -2.04, p = .042) and general psychopathology [z = -2.30, p = .021], with slightly reduced but very similar effect sizes to those reported for the full samples: r = .294 and r = .332 respectively. Once again, the clearest difference between the two samples was in positive symptoms [z = -2.35, p = .018] and, while the magnitude of this association was much less compared with the full group comparisons, it still represented a moderate effect: r = .339.

10.5 Discussion

In this chapter I have presented a direct comparison between a community sample of subjects who meet UHR criteria and a clinical sample of patients currently being seen by a specialist UHR service. Against my prediction, the evidence pointed to a significant difference in relation to migrant status. However, the main findings were that the clinical sample experienced more severe positive, negative and general psychopathology and a greater degree of functional impairment, while a greater proportion of the community sample were identified by Basic Symptom criteria alone.

Contextualising the findings

To understand these findings it is important to consider that the type of patients who present at OASIS is to some extent dependent on the referral process (Fridgen et al., 2013; Rietdijk et al., 2012; von Reventlow et al., 2014). The largest proportion of OASIS referrals

come from other health agencies, especially GPs who are responsible for 28% of referrals (Fusar-Poli et al., 2013c). So, for example, individuals who are referred to OASIS will be those whose symptoms are interpreted by the GP as being relevant for that service. This could potentially introduce some bias into the process leading to non-systematic differences in how well mental health problems are detected and who reaches specialist care (Maginn et al., 2004; Rietdijk et al., 2012). The ongoing education and training of potential referrers is therefore paramount for UHR recruitment strategies and risk enrichment from the general population to the clinical services (e.g. Addington et al., 2013; Reynolds et al., 2014).

In terms of how subjects have arrived into this study, the majority (76%) of the patients in OASIS are referred from within the health system (including GPs, first episode psychosis teams and mental health services; Fusar-Poli et al., 2013c), while just under a third of the community sample were engaged with health services at the time of interview. It should be acknowledged that in the present study, potential differences in pathways to care were not specifically examined between the clinical and community UHR groups. For example, it may be that the different groups had presented to different sources or GPs with different levels of training or psycho-education in recognising the UHR state. Moreover, less than a quarter (23%) of the community UHR sample had contacted their GP in relation to their symptoms. Since GPs are the usual target of specialist training promoted by the OASIS to detect and refer subjects at high clinical risk for psychosis (Reynolds et al., 2014), this may also partly explain why those in the community UHR had not had contact with OASIS, even if they were help-seeking.

Timing may also play an important role in making sense of these findings. Specifically, while the community UHR subjects were recruited to the study at a time unrelated to their symptoms or wellbeing, the point at which OASIS patients were interviewed was the point at which they sought help from a specialist UHR service. This act is likely to be underpinned by recent difficulties in functioning, which may go hand in hand with more severe symptoms. This is consistent with the greater functional impairment found in the clinical sample compared to the community UHR group. Furthermore, the clinical sample used in this chapter represents a subset of UHR patients who were willing and able to take part in research. These are likely to be OASIS clients with the least severe symptoms and the least functional impairment. It is therefore likely to provide a relatively conservative estimate of the differences between clinical and community groups. In this context, the functional differences between the two groups are even more striking.

For my first hypothesis I tested sociodemographic differences between the two groups. Against my prediction I found a clear indication that first generation migrants were over-represented within the community group and, while other differences were not statistically significant after multiple testing corrections, there was also a trend for women to be over-represented in the community group. It is possible that women and first generation migrants may have symptoms that are more often at levels which do not require specialist care, or may be better adept at coping with their experiences without specialist care. However, these findings could also be explained in terms of the referral process. One possibility is that the two groups had sought help from different agents. For example, individuals in the community UHR sample may have sought help from (health- or non-health-) agents who were less well trained to detect the UHR state than traditional OASIS referrers (i.e. GPs; Reynolds et al., 2014). They may therefore be less confident about detecting an UHR state in migrants than in other groups, particularly if there is uncertainty about what may be culturally appropriate. If such biases were present in the referral process this might lead to help-seeking individuals not receiving the most appropriate support, which would strongly advocate extensive training and education of all the community referrers. At present, however, the reasons for these findings are unclear, and the differences themselves would need to be replicated in a larger sample before they can be understood.

Although there was no evidence to support a difference in cognitive ability between the two samples, there were several striking differences in terms of symptom severity. The strongest differences were related to positive symptoms, in that individuals in the clinical UHR group reported positive symptoms that were more severe and greater in number. Differences in severity were driven primarily by the clinical sample being more likely to report unusual thought content and non-bizarre ideas, including paranoia, whereas the rates of perceptual disturbances were very similar between the two groups. This is consistent with previous findings that bizarre ideas and persecutory ideas may be most associated with distress (Armando et al., 2010; Yung et al., 2006a). The clinical group was also characterised by more severe negative symptoms and more severe general psychopathology, which may be associated with significant impairment (Fusar-Poli et al., 2014b; Mäkinen et al., 2008; Meyer et al., 2014), poor quality of life (Domínguez-Martínez et al., 2013) and increased help-seeking (Falkenberg and Fusar-Poli, under review; Kobayashi et al., 2011; O'Callaghan et al., 2010).

The clinical sample also showed a greater degree of functional impairment than the community UHR group, which could be explained directly by the greater severity of symptoms. The present findings supported this to some extent, with moderately strong negative

correlations found between symptom severity and poor social and occupational functioning (GAF-F) in the patient group, particularly for negative symptoms and general psychopathology. Nevertheless this was not true of the community UHR group, for whom only positive symptoms were associated with this kind of functional impairment. This is surprising given that negative symptoms and general psychopathology were particularly associated with distress and help-seeking within the community UHR group. However, associations with psychological functioning and global symptom level (GAF-S) showed almost the exact opposite pattern, with all three symptom types associated with psychological functioning in the community group but not in the patient group. One interpretation of this is that although the positive, negative and general symptoms may all be associated with subjective distress, the community group are not as impaired by their symptoms in their daily lives, and may be better able to cope than the clinical group. These findings tentatively suggest that there may be something qualitatively different in the way that symptoms affect the community group compared with the clinical group.

Finally I found important differences in the inclusion criteria groups represented in the two samples. The majority of the patient group (84%) met APS criteria, which is in keeping with reported figures for the service (89%; Fusar-Poli et al., 2013c). In contrast, UHR subjects in the community were comparatively more likely to meet BS criteria alone (40%) than were the patient sample (5%). One way of understanding this is in terms of the distress associated with symptoms. Evidence in the previous chapter showed that basic symptoms were generally associated with lower levels of subjective distress than other types of symptoms and also with lower levels of help-seeking in the community sample. Therefore those meeting BS criteria alone may simply be more able to cope with their experiences and less in need of support. Nevertheless, another way of understanding this is in terms of the referral process. Basic symptoms are rarely observable to others and so may be difficult for referrers to detect accurately, and may even be difficult for the individual to articulate without detailed questioning (Schultze-Lutter, 2009). In this context the greater proportion of basic symptoms in the community is consistent with the idea that positive symptoms may be more easily noticed and, in the UK, are more readily recognised as being related to psychotic disorder than are basic symptoms. Therefore if someone with UHR features is seen by a referrer they may be more likely to be referred to OASIS as opposed to a counsellor or other non-specialist services if they have strong positive symptoms than if they have subjective cognitive problems. A similar logic could also apply to self-referrals, since even if individuals are aware of non-positive experiences they may not think to connect them to psychosis. However, this remains at the level of speculation.

Finally, comparing just the APS subgroup from each sample revealed that the previous difference in positive symptoms was partly an artefact of the inclusion criteria, in that because more of the community group met BS criteria rather than APS criteria, positive symptoms were not prerequisite in this group. When analyses were restricted to the APS subgroup alone this association was greatly reduced (although still significant), suggesting that it was largely (although not entirely) explained by this fact. On the other hand, the magnitude of associations with negative symptoms and general psychopathology did not change as a result of this restriction, suggesting perhaps a greater stability in this association. This fits with recommendations in the literature that positive symptoms alone may not provide enough distinction between those who have a clinical need and those who do not (e.g. Simon et al., 2013).

Limitations

One key limiting factor was the lack of data available for the clinical sample at the time of analysis. In particular, the fact that only severity scores were available for CAARMS subscales means that potentially important information regarding the frequency of symptoms could not be investigated. Perhaps an even greater shame is the lack of information about the distress associated with symptoms, which would have helped to clarify some of the findings discussed above. On the other hand, the variance of frequency scores is to some degree constrained by the fact that all individuals met UHR criteria. Moreover, in the previous chapter it was shown that associations between distress and help-seeking were explained by symptom severity. However, without this information we can never be sure that we are getting the full picture of the symptomatic differences that may exist between the community and clinical groups.

Similarly, no clinical data were available for basic symptoms, while the assessment of cognitive ability was restricted by the lack of comparable measures. It would be useful to investigate the prevalence of BS criteria in the clinical sample, and the degree to which APS and BS criteria overlap. This direct comparison with the community sample could potentially elucidate much about their importance. Likewise a comparable IQ measure would have allowed me to test the hypothesis that more cognitive resources may be associated with lower levels of distress and help-seeking for the same symptoms (Brett, unpublished), or that low IQ may be a risk factor for a more severe UHR state as it is for psychotic disorder (Reichenberg, 2005). Nevertheless the data that were available have certainly enabled a starting point upon which future research can expand.

Finally, the work presented in this chapter is limited by the small size of the samples. While there was sufficient power to identify a number of significant differences, particularly in terms

of symptom severity, replication in a larger sample may clarify some of these associations and may reveal important differences in terms of demographic characteristics. This is discussed in more detail in Chapter 11 (p.171).

Conclusion

In this chapter I have provided some initial evidence that there may be both qualitative and quantitative differences between the clinical and community UHR groups. I have shown the clinical sample to be more severely affected in terms of positive symptoms, negative symptoms and general psychopathology, and the community group to be more often characterised by basic symptoms alone. Although the evidence for demographic differences may be weak, the potential implications for referrers are important and will be discussed in more detail in Chapter 11. Despite a number of differences from the clinical sample, to identify UHR status in the community is not necessarily a case of mistaken identity. In symptoms and in functioning the community UHR group appear to represent almost an exact midpoint between healthy members in the community and current users of the OASIS service.

V. DISCUSSION

CHAPTER 11 GENERAL DISCUSSION

The aim of this final chapter is to provide a synthesised overview of my thesis. It is intended to build on and draw together the more focused discussions that have concluded each of my Results chapters. I will begin by summarising the main findings in relation to the study aims. Next I will consider the methodological strengths and limitations of the work I have produced. I will then discuss the data I have presented as a whole, both within its own context and within the context of the wider literature, and discuss potential implications both for research and for clinical services. Finally I will outline some directions for future work which I believe would complement and build on the findings of the thesis.

11.1 Synopsis

In the introductory chapters I outlined some of the main issues regarding the UHR literature: primarily that UHR research has, to date, been largely confined to clinical help-seeking populations. Consequently the prevalence of these specific symptoms in the general population is unknown. The first and primary aim of this thesis was therefore to apply clinical assessments in the community to estimate the prevalence of people meeting UHR criteria in the general population. Following this it was important to establish whether the community individuals who met UHR criteria were suffering as a result and whether the symptoms they were experiencing led to any help-seeking behaviour. Finally, I compared the community UHR individuals that I identified with a sample of individuals who met traditional UHR criteria in a clinical context, to assess how these individuals might differ with regard to their demographic and clinical profiles. By addressing these aims it was hoped that I would achieve a better understanding of what the UHR criteria were actually measuring and what aspects of the criteria might be the most important for identifying individuals with a clinical need. It was also hoped that this study would contribute to the literature on psychotic experiences and the psychosis continuum, since estimates are based on a set of criteria that are already being used in clinical practice as the basis for symptomatic and preventative treatments.

11.1.1 Summary of main findings

The first challenge was to obtain a sample that was representative of the study population, namely 18-35 year olds in South London. The results presented in Chapter 7 were encouraging

and enabled the aims of the thesis to be addressed. The main findings from each of the subsequent chapters are summarised below in relation to the aims of the thesis.

The first aim was to estimate the prevalence of subjects meeting UHR criteria in the general population. In Chapter 8 I presented evidence that approximately 7% of the general population aged 18-35 met symptomatic UHR criteria based on the CAARMS. The addition of subjects who met BS criteria as measured by the SPIA-9 raised this estimate to just under 13%. Additional exploration of this community UHR group revealed the important finding that almost as many individuals met BS criteria as met PACE criteria. Moreover, only a minority of individuals met both PACE and BS criteria; the majority of subjects identified as meeting UHR criteria were uniquely identified by just one set of criteria. Crucially, this would mean that 40% of those identified as 'at risk' would not be seen by a high risk service that relied only on PACE criteria.

My second aim was to investigate whether the UHR state in the community was associated with distress, impairment and help-seeking, as it is in clinical services. My findings presented in Chapter 9 indicated that the community UHR group often reported subjective distress in relation to their symptoms, exhibited lower functioning, and showed a greater need for care than those who did not meet UHR criteria. The community UHR group also showed elevated levels of help-seeking behaviour, specifically from professional health services. Of the 30 individuals identified, 19 perceived a help-seeking need and, of these, 9 had already sought help from professional services. Additional analyses indicated that help-seeking did specifically occur in relation to symptoms associated with an UHR state, although this was lower for basic symptoms. Taken together, the findings suggested that UHR status in the community was associated with a clinical need. However, the data also suggested that the problems experienced may be less severe than in those who presented to clinical UHR services.

Finally, Chapter 10 addressed my final aim: to compare those who meet UHR criteria in the community with a clinical sample of patients who were currently seeking help from a specialist UHR service. The main finding was that the clinical sample appeared to be more severely affected than the community UHR group. As well as a greater functional impairment, the clinical sample reported more severe positive and negative symptoms, and a higher level of general psychopathology than the community UHR group. Individuals in the community sample were also more likely to meet BS criteria alone, whereas the clinical sample were almost entirely characterised by people with attenuated positive symptoms. This difference in clinical profile partly accounted for the higher severity of positive symptoms in the clinical group but did not affect the differences in negative symptoms and general psychopathology between the two samples. Together these findings suggest that there may be more than just

quantitative distinctions between clinical UHR patients and individuals who meet UHR criteria in the community.

11.2 General strengths and limitations

In order to appreciate the level of caution with which the above findings should be interpreted, it is important to recognise that the present study was not perfect. In addition to those highlighted in individual chapter discussions, some general strengths and limitations of the study are now discussed. These relate primarily to the design and methods used in the study and apply to the findings of all chapters.

Use of the CAARMS

The way the CAARMS was administered in the present study differs from its conventional use in two ways. Firstly, although there was good reason for taking this approach (explained in Chapter 5), opting not to include the functioning criterion (30% decline or persistent score below 50 on GAF-F) for the definition of the APS group (introduced by Yung et al., 2006b) could potentially create an artificial distinction between the clinical and community groups, exaggerating the difference in functioning shown in Chapter 10. However, in clinical practice this criterion is not adhered to inflexibly; if an individual is symptomatic and help-seeking they will not be turned away. For example, in the patient sample used in Chapter 10 the highest GAF-S and GAF-F scores were 75 and 80 respectively, higher than the median GAF scores in the community sample. As a result, the subjects who met symptomatic UHR criteria in the present study may well have been taken on as clients if they had been referred to OASIS. Furthermore, the North American variant of the PACE criteria (the COPS; Miller et al., 2003) does not include a functional criterion. The recent addition of a functional element to the original PACE criteria was justified on the basis that a functional decline was shown to be predictive of a transition to psychosis (Cannon et al., 2008; Ruhrmann et al., 2010), but the absence of this does not preclude individuals experiencing a current need for care. Excluding it from the present study may make the results more comparable with another study that used this approach (Kelleher et al., 2012d), which reported that the addition of the 30% functional decline criterion reduced the population prevalence from 7.7% to 0.9%. In the long term, the research above suggests that the functional criterion could be an important way of differentiating people with occasional psychotic experiences from those who are really at high risk of a disorder, but in terms of identifying something clinically meaningful, some have argued that this may be too insensitive (Schimmelmann et al., 2013). This hypothesis could be tested by following up the present study sample and investigating long term outcomes.

The second difference is the time period investigated using the CAARMS. While the CAARMS is most often used to investigate symptoms with respect to the last year, the present study focused only on the past three months (the same period examined by the SPIA-9). While this could again been seen as a limitation in terms of comparability, I would argue, for the reasons outlined in Chapter 5 (p.70), that it actually strengthens the comparison with the clinical sample. The shortened time span represents a more conservative approach since it would exclude individuals who had experienced transitory symptoms within the last 12 months that had not reoccurred or persisted during the three months prior to interview. This is important firstly because persistent psychotic experiences have been shown to be more problematic (Dominguez et al., 2011; Kaymaz et al., 2012; Wigman et al., 2011), and secondly because it is unlikely that those who approach clinical UHR services would do so on the basis of symptoms that had not occurred recently, so a three month period should provide a suitable comparison. Furthermore, a shorter time span is likely to improve the reliability of recall, since details about the severity, frequency and context of symptoms may more easily be forgotten over the course of a year.

Sample size

Perhaps the main limitation of the present study was the small size of the samples. While the study was sufficiently powered to estimate the prevalence of UHR symptoms in the general population, the size of the community UHR subgroup (30 individuals) limited the power of further analyses. In particular, explorations of help-seeking within this sample or comparisons with the clinical UHR group were compromised by the small number of individuals available and the wide confidence intervals that were produced for estimates as a result. Nevertheless, recruiting a study sample of n = 208 using epidemiologically rigorous methods, with a single researcher working full-time, took approximately two and a half years. This was facilitated by two larger studies which were involved in the initial recruitment of participants. It would therefore take a great deal of work to identify substantially larger numbers of individuals meeting UHR criteria in the community. For example, assuming a prevalence of approximately 13% (from the present study), a sample of 769 participants would be needed to identify 100 individuals meeting UHR criteria. Recruitment of such large numbers could be facilitated by compromising on the quality of the assessments, such as conducting interviews by telephone rather than face to face, or by using simpler instruments than the CAARMS. Another option would be to use a less rigorous sampling strategy, such as convenience sampling methods or using pre-defined cohorts such as schools. The fact that the

sample in the present study is the first of its kind in the literature highlights the logistical difficulties in recruiting large community samples of this type.

Bias, chance and confounding

Bias in research has been defined as "a systematic distortion of a statistical result due to a factor not allowed for in its derivation" (Oxford Dictionary, 2014). Unlike the impact of chance and confounding, bias occurs independently of the sample size (Pannucci and Wilkins, 2010) and must therefore be addressed by the study's design and implementation. In order to be completely confident in the findings of a study, forms of systematic bias need to be eliminated. Bias can take a number of forms. Those most relevant to the present study, namely selection bias and information bias, are discussed below. Steps taken to mitigate the impact of potential biases are also discussed.

i. Selection bias

Selection bias here refers to systematic differences in likelihoods of participating in a particular study taking place by either exposure or outcome. In particular, two types of selection bias are relevant for the present study: firstly sampling bias, which relates to the likelihood of being invited to take part, and self-selection, which relates to the likelihood of accepting this invitation. The primary source of the former is the sampling method. In the present study I have described the epidemiologically rigorous approach taken to sampling, which will have gone a long way to controlling the impact of this. No method is perfect, and it is possible that there may be biases in terms of which individuals each recruitment method is likely to identify. However, by combining two independent methods it was hoped that the two may have counteracted one another and that the impact of these biases may therefore have been diluted. For example, if a person is rarely at home it may be difficult to recruit them via PAF sampling, which requires a visit in person; however, the letter approach of GP sampling may be more effective. Conversely, while approximately 97% of Lambeth and Southwark residents are registered with a local GP[8], residents often change address without notifying their GP so patient lists may not be completely up to date, whereas PAF recruitment is based on a complete list of residential addresses and is not dependent on the residents themselves having registered. This is not to say that all biases can be eliminated by this dual approach; however, the fact that the obtained sample was broadly representative of the study population based on demographic measures is encouraging. Furthermore I have outlined steps that were taken to use inverse probability sampling weights to control for discrepancies.

[8] Based on data from the Health & Social Care Information Centre (2012)

The extent to which self-selection influenced the findings is more difficult to quantify. While the representativeness of the sample is again consistent with there not being demographic biases involved, the possibility that other factors may have had an impact cannot be ruled out. In particular, it is worth considering self-selection in relation to symptoms. On the one hand individuals who have experienced psychotic phenomena may be particularly interested in taking part in research related to it, particularly if it is something they have not spoken about with others. On the other hand, individuals who may be suffering greatly or struggling to function may be less able and less willing to take part in research. In particular, strong tendencies towards paranoia might make an individual unwilling to answer the door to strangers or actively respond to an invitation to be part of research, or to be guarded about disclosing their experiences. Self-selection may also be influenced by attitudes towards health services in general, in that some individuals may feel duty bound to respond to something sent from their GP, while others may simply disregard it, or even feel distrustful towards it. Overall, the complexity of this issue makes it difficult to predict who is likely to self-select and this may mean that it did not have a net influence in a particular direction. In addition, steps taken towards mitigating the effect of self-selection included appropriately incentivising participation, ensuring that participants were informed about confidentiality and about the purposes of the study, being flexible with regards to appointment times and lengths of appointments where necessary to remove obstacles to participation. Through a combination of these actions, it is hoped that the potential impact of self-selection was significantly reduced.

ii. Information bias

Information bias refers to systematic differences in the way that information is collected between individuals. One form of this is observer bias, which is the idea that the interviewer (me) might rate symptoms and experiences differently in some individuals compared with others, based on a particular characteristic. As the study was mainly cross-sectional, no prior information was known about the majority of participants. However, participants who were recruited via the SELCoH study were an exception to this, in that their status with regard to the PSQ at time 1 was known at the time of interview. Nevertheless, questionnaires were standardised, assessments were rated according to clear guidelines and I received thorough training on the CAARMS. Together these measures should be sufficient to protect against such a bias. The fact that the two sampling methods (which roughly equate to the two larger studies) did not lead to significant differences regarding clinical measures is also encouraging.

Other forms of information bias relate to the quality of the information provided by the participant. One that is relevant to the present study is social desirability bias, which is the tendency of a subject to give answers based on what they think will be acceptable. Several measures used in the present study could be vulnerable to social desirability bias, particularly those related to drug use, childhood trauma and, most importantly, psychotic symptoms. In addition to emphasising the confidentiality of the appointment, one step taken to protect against this bias was to blind participants to the hypotheses of the study. This was to discourage subjects either playing down or concealing any symptoms they had, but also to discourage them exaggerating or inventing symptoms. In addition, the tone of the interviewer was kept neutral and non-judgemental, ensuring that participants felt safe and able to divulge information without concern or embarrassment. The finding that prevalence rates and associations with risk factors are generally in keeping with findings of past literature is hopefully a sign that the amount of (new) bias introduced in the present study was minimal.

Finally, recall bias may also be important. This refers to systematic differences in the quality and accuracy of information recalled by a participant. This is important whenever information is obtained retrospectively and could potentially have influenced the quality of information reported with regards to symptoms. In particular, there may also be differences in the accuracy of symptom information collected between participants who were experiencing cognitive disturbances and memory difficulties and those who were not. This is particularly true in relation to lifetime and childhood experiences. However, the present study focused mainly on symptoms and experiences that occurred in within a relatively recent period. For example, the timescale of the CAARMS was reduced from 12 months to 3 months, thus reducing the likelihood of forgetting about symptoms that may have occurred within this time. Therefore the impact of recall bias is likely to be low compared to other studies.

iii. Chance

In theory, there is a chance that any observation could be a result of sampling error rather than reflecting a 'true' association present in the population. The likelihood of rejecting the null hypothesis when it is in fact true (Type I error) is inflated when several tests are conducted under the same hypothesis. By correcting for multiple testing, the probability of a Type I error for each hypothesis was kept at 5% ($\alpha = .05$). However, it should be acknowledged that there is still the possibility that some of the associations observed in the present thesis might have been the result of chance. On the other hand, Type II errors refer to the likelihood of failing to reject the null hypothesis when it is in fact false. The level of statistical significance attached to some of the findings presented was relatively low partly as a result of the low sample sizes,

particularly for subgroup analyses. By correcting for multiple testing, it is possible that some 'true' associations may have been reported as non-significant. To reduce the chance of such results being missed, any results that appeared to indicate a true effect were given some attention.

iv. Confounding

Confounding occurs when a third variable is associated with both the exposure and, independently, the outcome of interest and is not on the causal pathway. In the present study potential confounders were identified *a priori* and their effects controlled for with adjustments to the analyses, as described in Chapter 6 (p.90). One danger of using this approach is that the inclusion of too many confounders can undermine the precision of statistical estimates and potentially obscure a true association (Susser et al., 2006, p. 147). This is particularly true of tests where statistical power is already low. Therefore, in line with current conventions, unadjusted analyses were presented first, followed by adjustments for confounders. In this way the specific impact of including the confounding variables can be clearly seen. The number of confounders used was also kept to a minimum, to maximise the clarity and interpretability of findings. Partly as a consequence of this, the possibility that associations may have been under-adjusted should also be acknowledged. However, since we know very little about the community UHR group it was felt that under-adjustment was the lesser of two evils. Furthermore, as in all studies, there is the possibility that confounding may have occurred in relation to unidentified and unmeasured variables, but it may be up to future studies to assess whether this has been the case.

Generalisability of the sample

The participants used in this thesis were subject to two inclusion criteria: age and residency. The reason for doing this was to be able to draw the most accurate comparisons with the OASIS specialist UHR service which serves the same local population. The sampling methods used were rigorous and representative and consequently the results of the present study should be generalisable to the study population. However, this focused approach may limit the extent to which results can be generalised to other populations. The South London boroughs of Southwark and Lambeth are demographically and socioeconomically diverse areas with a high concentration of risk factors for psychosis: high urbanicity, large populations of ethnic minorities, and areas of high socioeconomic deprivation. The 18-35 years age range is thought to be the most common time for psychosis to develop and is thus the crucial period for early intervention (Häfner et al., 1993; McGorry et al., 2003). Taken together, this might

lead to the prevalence of the UHR state in the present study being higher than in samples recruited from other geographical areas and broader age ranges, since variation in incidence rates in relation to different socio-economic environments is a well-established feature of psychotic disorders (e.g. Kirkbride et al., 2006). Nevertheless, it is also true that specialist UHR services such as OASIS and the PACE clinic are relatively rare. Consequently, in areas not served by specialist services, with no clear path for referral, it is possible that people meeting UHR criteria might be more likely to remain in the community or in primary care than to enter the mental health care system. Lastly, findings in relation to the use of health services are to be considered specifically within the context of free healthcare available in the UK. Patterns of help-seeking behaviour therefore do not take account of additional factors such as health insurance and financial barriers to care that may be relevant to other populations.

Causality

Finally, it is also important to mention causality. Although not the primary aim, the present study has identified a number of associations between UHR status, different risk factors, and help-seeking behaviour. As a cross-sectional study, this thesis does not contribute to our understanding of causal pathways between risk factors and UHR symptoms. One of the study's key strengths is in directly asking about which symptoms specifically led to help-seeking behaviour. However, we cannot know from this data exactly what caused the help-seeking act; whether it was simply related to the experience of the symptom or whether other factors were important.

11.3 Interpreting the findings

Having acknowledged the methodological limitations of the present study and highlighted some of its strengths, I will now bring focus to the findings themselves. The above limitations notwithstanding, the findings presented in this thesis provide an important insight into the nature of the UHR state in the general population and speak to a number of important themes.

11.3.1 What does it mean to be UHR in the community?

The findings of the present study raise a number of key questions. Firstly, is it valid to apply UHR criteria to a community sample, as opposed to one that has presented to a clinical high risk service? Despite the fact that the present study is not the first to attempt this (e.g. Schimmelmann et al., 2011; Yung et al., 2005) and that the testing of these criteria in an epidemiologically-defined general population sample has been highlighted as a required next step for validating the criteria themselves (Schultze-Lutter et al., 2013b), this remains an important question. While various UHR criteria have been examined in general population

samples (e.g. Kelleher et al., 2012d; Meng et al., 2009), the BS and PACE criteria have only been validated in clinical samples. As a result, the clinical or functional significance of meeting UHR criteria in the general population is not clear. In the present study I found that just over half (52%) of those meeting UHR criteria in the general population were help-seeking, albeit from non-health agencies or health professionals other than a clinical high risk service. Furthermore, two thirds of the community UHR group (66%) reported one or more unmet need for care, while 65% of the group at least perceived a help-seeking need, even if they had not yet sought help. Other than not perceiving a help-seeking need, the reasons for not seeking help, and specifically for not being in contact with specialist UHR services, may represent a combination of a lack of awareness of available services and issues with the referral process (discussed in more detail below). However, it does appear that in general the UHR state is often associated with help-seeking. Furthermore I have shown that meeting UHR criteria in the general population is associated with impaired functioning compared with the rest of the sample, at least in those meeting PACE criteria. Taken together, these findings indicate that there is a need for care in at least some of the UHR community group.

Do *all* of the people meeting UHR criteria in the community have a genuine help-seeking need? It is difficult to answer this question on the basis of a single cross-sectional assessment, as it is possible that subjects who were not help-seeking when first assessed may later become help-seeking, for example if their symptoms persisted or got worse. Because of this, a follow up study would be necessary to address this issue. Another difficulty is that although many individuals report being distressed by their experiences, distress is by nature very subjective and it is hard to know what level of distress is likely to have a day to day impact on the life of a given individual and at what stage this translates into a need for help. Some may feel distressed at the time but otherwise feel able to cope with the symptoms, while others may not be distressed much at all. It is also difficult to identify whether basic symptoms experienced are truly problematic since they were associated with very little specific help-seeking compared with other symptoms measured. As with other symptoms, the context may be extremely important for determining this need. Nevertheless some individuals surely do represent a genuine help-seeking need. In the community UHR group I identified individuals who were both distressed and help-seeking, but had simply not been in contact with specialist clinical services. While it's possible that they may be getting adequate support from GPs or counsellors, friends or family, there's also the chance that they are not and it would therefore be these individuals that services like OASIS should be trying to reach.

Do those who meet UHR criteria in the community have the same high level of risk of developing psychosis as those ascertained through high risk clinical services like OASIS? As I

have mentioned previously, the most recent version of the PACE criteria requires that attenuated psychotic symptoms are associated with a recent decline in functioning, a requirement that could not be applied in the present study. Furthermore, the PACE criteria were derived from studies of subjects who presented to high risk services, rather than those identified in the community. It is therefore possible that the level of risk in the community UHR group is lower than in those who present to high risk clinical services. On the other hand, the current literature suggests that those who self-report any positive psychotic experience may be at threefold elevated risk for psychotic disorder (0.6% yearly transition; Kaymaz et al., 2012). In the present study, the community UHR group were identified on the basis of a detailed face to face interview, with specific requirements for the severity, frequency and recency of symptoms. Therefore the risk of transition in this sample might be greater than for community psychotic experiences. One useful way of thinking about the community UHR group is with reference to Valmaggia et al's (2013) finding that UHR patients could be classified into groups of differing risk for transition. The mildest class within this paper was associated with a 4.9% risk of transition within two years. However, the average GAF scores of even this group (around 61) are still much lower than the community UHR group (around 70). The community UHR group might therefore represent a milder class still, and thus one might expect only a marginally elevated risk compared with those who do not meet UHR criteria. However, this issue requires investigation through the longitudinal follow-up of my sample. Nevertheless, transition has been shown to be associated with a variety of other factors in clinical samples including deficits in cognition and functioning, higher levels of negative symptoms, and concurrent substance use (see Fusar-Poli et al., 2013b for review). Transition risk is therefore likely to be as heterogeneous across the group as the clinical profiles.

However, it is not just about risk. Those who meet UHR criteria in the community are symptomatic at that moment and I have shown that for many this is associated with distress and functional difficulty. In all, they probably have a greater need for care compared with members of the general population who do not meet UHR criteria. Yet, on the evidence of Chapter 10 they do not appear to reach the same levels as those already in contact with UHR services. In fact, in terms of average functioning and symptom severity scores, the community UHR group appears to be almost an exact midpoint between the clinical sample and the rest of the general population. Conceived in the context of the psychosis continuum, the community UHR group may represent individuals on the same continuum of experience as the clinical group, which is simply further along the spectrum, experiencing more symptoms and with greater intensity. It is also possible that the clinical group represent people at a later stage, and that some of the community UHR sample will develop more severe symptoms and functional

difficulties over time. Nevertheless, my findings could also reflect the presence of distinct subpopulations. The differential associations found between risk factors for psychosis and different types of UHR symptoms Chapter 8 could suggest that those meeting BS criteria alone may be qualitatively different from the clinical UHR sample who almost unanimously met PACE criteria, while those meeting PACE criteria in the community may simply be quantitatively different. Differences observed in relation to help-seeking support this hypothesis. However, the difference between clinical and community samples may also be a function of referrers to OASIS being more likely to perceive positive symptoms as suggestive of psychosis than subtle cognitive changes.

11.3.2 Additional themes

In addition to the main findings, exploration of secondary hypotheses within each chapter revealed a number of themes that are worthy of discussion.

The role of positive symptoms

The definition of the UHR state in clinical practice has been dominated by a focus on positive symptoms. A secondary aim of this study was to examine a range of different symptoms, so that the associations and importance of basic symptoms, negative symptoms and general psychopathology could be assessed alongside positive symptoms. My findings have provided evidence that the UHR state in the community extends beyond positive psychotic symptoms.

i. The role of negative symptoms

The vast majority of those presenting to clinical UHR services are characterised by positive symptoms (e.g. Fusar-Poli et al., 2014b). Nonetheless I have shown that in the general population those meeting BS criteria were as prevalent as those meeting APS criteria (both 7%), while those meeting criteria for ANS were even more prevalent (9%). The ANS criteria are experimental and have not yet been validated in terms of risk for psychosis. Nevertheless, my findings indicated that negative symptoms were associated with slightly higher levels of distress than positive symptoms and general psychopathology, while basic symptoms were shown to be the least distressing. Similarly, of the four types of symptoms investigated, negative symptoms were also the most likely to elicit a help-seeking response. Although only reported by 17 individuals of the community UHR group (n = 30), five of these (31%) specifically sought professional help for them. Nevertheless inferences were not made because of the small sample size, so it is not clear whether this association exists outside of the present sample. In schizophrenia, patients have been found to be less subjectively aware of

their negative symptoms and consequently less concerned by them (Amador et al., 1994; Selten et al., 1998). However, it is possible that this is not the case for UHR subjects because they have a higher level of insight (Lappin et al., 2007). The present findings support the hypothesis that negative symptoms may be more subjectively concerning and more easily recognised in this group. If true, this could have implications for treatment, since there would in theory be a greater chance of success if the patient recognised that the negative symptoms were a problem.

Finally, the clinical UHR sample not only showed more severe levels of positive symptoms than the community UHR group, but also more severe levels of negative symptoms and general psychopathology. This association with the latter two forms of symptoms was not affected by the removal of the BS subgroup, suggesting a robust difference in negative symptoms and general psychopathology between the community and clinical UHR groups. Together this suggests that the presence of negative symptoms may be an important indicator of which UHR individuals are the most unwell and may therefore be of relevance in addition to the attenuated positive criteria traditionally employed. Consistent with this, negative symptoms are associated with the worst clinical and functional outcomes in patients with schizophrenia (see Mäkinen et al., 2008 for review).

ii. The role of common mental disorders

At the same time, symptoms of common mental disorder (as measured by the general psychopathology score on the CAARMS) were ubiquitous within the community UHR group. In addition to being important in the way mentioned above, the presence of general psychopathology appeared to explain many of the associations with the UHR state, such as impairment in psychological functioning and more professional help-seeking, and partially explained others, such as impairment in social and occupational functioning and a greater need for care. In my pilot work I found that psychotic experiences in absence of common mental disorder appeared to be somewhat benign, whereas the two combined conferred much greater odds of help-seeking and of suicidality. This is consistent with the idea that distress may accumulate as multiple symptoms develop, leading to more help-seeking behaviours (Fusar-Poli et al., 2014c). Using the longitudinal subset of my sample, I have also presented evidence that the combination of psychotic experiences and common mental disorder predicted far greater odds of meeting UHR criteria around three years later, tentatively suggesting that this may be a key factor in distinguishing individuals who are likely to develop further problems from those whose symptoms are likely to be transitory.

iii. A revised role for attenuated positive symptoms

Taken together, these findings provide support for the idea that the UHR state cannot be understood in terms of positive symptoms alone. Positive symptoms are commonly reported in the general population and, like negative symptoms, are not specific to psychotic disorders (Linscott and van Os, 2013; van Os et al., 2009; Yung et al., 2006a). My findings indicate that comparable levels of negative symptoms and basic symptoms may be present in the community, suggesting that positive symptoms may therefore be overrepresented in clinical UHR samples. This raises the question: why do we exclusively focus on them? There are many answers to this. The first is that the assessment of positive symptoms is fundamental for the predictive power of the CAARMS and other UHR assessments, leading to the identification of enriched samples with around a 30% risk of developing psychosis within two years. However, this is not due to the impact of positive symptoms alone. Rather, positive symptoms are an index of greater psychopathology. They are often associated with concurrent negative, general and basic symptoms, particularly in clinically derived samples (e.g. Fusar-Poli et al., 2014b), and individuals who experience these additional symptoms may be at greatest risk of a range of poor outcomes (e.g. Alderman et al., 2014; Michel et al., 2014; Schultze-Lutter et al., 2014a; Valmaggia et al., 2013). Another important aspect is that positive symptoms are easier to define and to recognise objectively than other kinds of psychotic symptoms, particularly negative symptoms which can be present in a range of disorders such as depression and are difficult to diagnose. Moreover, this is consistent with the idea that in the UK, the links between positive symptoms and psychotic disorder are more readily understood than are the links with basic symptoms (outside of specialist services). In this sense, UHR individuals who are characterised by positive symptoms are easier to identify and referrers such as GPs or family members may be more likely to direct them to specialist UHR services. My findings are consistent with the notion that other symptoms may be equally important for determining clinical need. The clinical implications of this and other findings are discussed in section 11.5 below.

Demographic trends and community UHR status

i. Gender

There were a number of surprising findings with regard to gender. In particular, there appeared to be a strong association between being female and meeting UHR criteria in the community. Given previous findings indicating that being male is a risk factor for psychotic disorder this was unexpected, but it is not unheard of, and has been reported previously in a

number of individual studies of psychotic experiences (e.g. Ronald et al., 2014; Yung et al., 2009; Zammit et al., 2013). Additionally, although it did not reach statistical significance, there was a trend that suggested a larger proportion of females meeting UHR criteria in the community than in the clinical sample. This combination of findings is interesting as it indicates that it may be something specific about the community UHR state that makes it more common among women. Stratifying this association by UHR subgroup indicated that this was not simply being driven by basic symptoms, but rather was present to a similar degree for both basic symptoms and attenuated positive symptoms. One possible explanation for these findings is that women may be better able to cope with their experiences than men. For example, women have previously been found to use a wider range of coping styles (Lin et al., 2011). Consequently UHR symptoms may be more prevalent among women in the community without worsening to a degree that elicits help-seeking from a specialist UHR service. Another possible explanation might be that the method of identifying UHR individuals in the present study may be more likely to identify an overlap with affective common mental disorders, such as anxiety and depression, which do tend to be found more often in women (e.g. Piccinelli and Wilkinson, 2000). These explanations are not mutually exclusive. Both are consistent with the speculation that women who seek professional help may do so from more generic services because their UHR symptoms occur more in the context of a common mental disorder and thus these services may be sufficient. However, both are also consistent with previous findings that women make more help-seeking contacts than men prior to presenting at an early intervention service (Fridgen et al., 2013).

On the other hand, another possibility is that ideas such as these may influence the referral process by which clients are put in contact with OASIS. For example it is possible that GPs and other non-specialist sources of help may interpret UHR symptoms differently in women than in men, and may be less likely to see them as related to psychosis and more likely to treat them as part of a common mental disorder. This is consistent with previous findings that for early psychosis, referral strategies (as opposed to screening strategies) tend to be biased towards recruiting young men (Rietdijk et al., 2012). Taken together, these findings may have clinical implications, which are discussed in section 11.5 below. However, it is also important to acknowledge the possibility that clinical and community groups may have differed in their pathways to care. The two groups may have been in touch with different potential referrers, some of whom may be more aware of clinical UHR symptoms and specialist services than others, including trained versus untrained GPs (Reynolds et al., 2014). Unfortunately this could not be addressed in the present study.

ii. First generation migrants

Finally, there were also a number of surprising findings related to first generation migrants. Migrancy was not associated with meeting UHR criteria in the community, although ethnic differences hinted that second or third degree migrant status may well be. However, first generation migrants were more likely to seek professional help for psychological or emotional problems than subjects born in the UK. Nevertheless, findings in the previous chapter showed that the community UHR sample contained a much larger proportion of migrants than the clinical sample, suggesting that this trend for help-seeking may not translate to specialist services like OASIS. As above, this pattern of results could be explained in terms of the referral process. For example, it is possible that GPs and other referring agents may be less confident about interpreting the symptoms of a first generation migrant as being related to psychosis, particularly if there are cultural differences between the agent and the subject. However, it is important to acknowledge that the numbers in these subgroups were small so this finding would again need replication in a larger study.

11.4 Contribution to past literature

To date, almost all research on the Ultra High Risk group has been based on help-seeking populations. It is important to acknowledge the ways in which the findings of this thesis may provide a unique contribution to the wider literature and thereby enhance our understanding of the UHR state.

Prevalence of UHR symptoms

The present study has added new data to a small but growing pool of knowledge about the distribution of 'high risk' symptoms in the general population. The present study is the first to examine both the PACE and BS criteria in an epidemiologically-derived community sample of young adults, analogous in age to those presenting to specialist services for 'clinical' UHR subjects. It builds on Schimmelmann and colleagues' (2011) pilot study that used telephone interviews of a small Swiss general population sample of comparable age range, by using a larger sample and conducting face to face interviews. The estimate of the prevalence of basic symptoms in the present study (7%) is slightly higher than reported elsewhere (around 3%; Schultze-Lutter et al., 2012) but to my knowledge this is the first time that the prevalence of basic symptoms has been estimated in a non-German-speaking sample. Furthermore, it is a strength of the present study to have demonstrated the impact that using multiple UHR criteria has on the prevalence of the UHR state. The finding that subjects were most often

uniquely identified by a single set of criteria may have clinical implications, which are discussed in section 11.5 below.

Help-seeking in UHR

Perhaps the most important contribution of this study has been to demonstrate that some individuals in the community not only meet UHR criteria but are also distressed, functionally impaired and help-seeking. Previous studies (Kelleher et al., 2012d; Schimmelmann et al., 2011) that have examined the prevalence of the UHR state did not assess the latter features, so the effect they had on the individual or their potential clinical significance was unclear.

The finding that around half of the UHR group were already seeking some form of help challenges the notion that those who are in contact with specialist UHR services are 'help-seeking' whereas those who are not should be described as 'non-help-seeking'. In fact, my findings indicate that individuals experiencing symptoms associated with the UHR state may seek help from a range of different sources. Previous studies of help-seeking have focused primarily on clinical help-seeking: my data indicate that this often extends to non-professional sources of support.

The decision to apply the CAARMS measure of subjective distress to all symptoms reported[9], including those on the SPIA-9, has revealed some particularly useful findings. This thesis is consequently the first work to show differences in the relative distress and specific help-seeking elicited by different clinical features associated with the UHR state, with basic symptoms appearing less likely to lead to distress and help-seeking. This is interesting from a community perspective in terms of understanding which symptoms are and are not specifically likely to elicit help-seeking behaviour. However, it would also be beneficial to compare these to similar research conducted with clinical populations, to understand whether and where differences may exist.

Methodological implications

This project is also set apart by its unique sampling method, producing a sample that is broadly representative of the South London population, as shown in Chapter 7 (p.97). The differential results of the two sampling methods used have been investigated and discussed, and these may have useful implications for the design of other studies. Certainly it may help researchers to be aware of the subtle differences in the type of individuals recruited by each method, in case this may be important for the outcomes they are examining.

[9] This is usually only used in conjunction with positive symptoms.

Moreover, the face to face interview approach used in the present study found similar prevalence rates to previous face to face interview findings (Kelleher et al., 2012d) but much lower than symptomatic prevalence rates for symptoms of the Section 3 DSM-5 diagnosis 'Attenuated Psychosis Syndrome' (very similar to the APS group) (Schultze-Lutter et al., 2013a). These findings potentially raise the concern that the two methods may not be entirely comparable. Findings of the present study may therefore be best compared with other face to face interview studies conducted in future.

11.5 Clinical implications

In revealing the UHR state to be prevalent in the general population and associated with distress, functional impairment and a need for care, I have identified an unmet need in the community. The relatively high prevalence of basic symptoms and negative symptoms calls for more attention to be paid to these features in addition to the attenuated positive features which have traditionally characterised the UHR state. In particular, negative symptoms and common mental disorder may be relatively greater sources of distress and may be the most likely symptoms to lead to help-seeking, in line with findings in the literature (Falkenberg and Fusar-Poli, under review; Schultze-Lutter et al., 2013a). The present findings suggest that basic symptoms experienced in isolation may not be associated with significant functional impairment, and may only be associated with low levels of distress and help-seeking. However, previous findings have shown that BS criteria in conjunction with PACE criteria may be more predictive of a transition to psychosis than meeting PACE criteria alone (Ruhrmann et al., 2010). Therefore it may be of clinical benefit to identify those currently meeting BS criteria so that they can be monitored and immediate help can be sought if additional positive symptoms emerge. Likewise, a similar approach may be appropriate for those meeting the experimental ANS criteria, given that additional negative symptoms also confer a greater risk of transition and poor functioning (Demjaha et al., 2012; Valmaggia et al., 2013).

The finding that two thirds of the community UHR group perceive a help-seeking need and yet none had made contact with OASIS also has clinical implications. Assuming that UHR individuals are best supported in specialist UHR services, it is important that referral processes are improved to ensure they can reach these services. In the past, education programmes focused on GPs have been shown to be effective (Reynolds et al., 2014). However, the most common sources of support throughout the sample in the present study were friends, who may be more difficult to educate directly. This may call for more public spreading of information, perhaps through widespread community education programmes as have been attempted in Canada (Addington et al., 2008), although these can become expensive. Another

option could involve utilising the internet and social media as a potentially cheap and effective way of reaching many individuals, as is being currently trialled in the US (Birnbaum, 2014).

In demonstrating differences between the community UHR group screened in my sample and the clinical UHR group referred to OASIS, my findings suggest that the two approaches to recruitment may reach different types of individuals. Although unconfirmed at present, it is likely that the transition risk would be much lower among the screened community UHR group. However, that is not to say that many would not benefit from having access to the specialist clinical services and it is possible that intervening early in this way might prevent more individuals from becoming more symptomatic. Finally, my results tentatively suggest that more awareness may need to be raised among primary and secondary care services about the potential impact of referral bias, ensuring that education and training programmes include issues such as identifying UHR features in women and in migrant populations, which might otherwise be causing difficulty.

11.6 Future work

The clearest avenue for future work would be a longitudinal follow up of this community UHR sample (as well as those who did not meet UHR criteria) to determine their clinical and functional outcomes. Firstly it would be useful to look at the transition rates, both for psychotic and for nonpsychotic disorders. This would help us to understand better the respective significance of the symptoms measured as precursors to more severe mental disorders. It would also be important to look at recovery as a major outcome, and hence predictors of resilience. Similarly and perhaps more importantly, a follow-up study should also look at the functional outcomes of these individuals. It would be particularly informative to focus on the role of non-positive symptoms, and especially to follow up those who met BS criteria (who appear to be less ill at present) and those who met the experimental ANS criteria, to ascertain the different trajectories upon which these differing profiles may place individuals. I would hypothesise that those individuals who met multiple UHR criteria might be the most at risk of problematic outcomes going forwards, in line with recent findings in relation to BS criteria and negative symptoms (Michel et al., 2014; Schultze-Lutter et al., 2014a).

It would also be interesting to follow up the sample with regards to help-seeking behaviour, to see whether and how help-seeking changes over time. For example, whether those who had sought help only from informal sources would go on to seeking help from professional health services, and similarly whether those currently in contact with nonspecific health services would begin to seek help from specialist mental health services as symptoms progressed. Undertaking such a project would ideally require a number of follow up

assessments extending over several years (the longer the better). It would therefore be an ambitious undertaking and issues of attrition that inevitably occur in longitudinal studies may be a particular problem given the small sample size to begin with. A more feasible (but less informative) option might be to use health records to follow up these individuals over time and to note their service contact and any future psychiatric diagnoses. The majority of participants agreed to being re-contacted in future and for their GP records to be accessed.

In the meantime, this work would certainly benefit from replication in a larger sample. Several of the associations reported in this thesis indicate that the sample was to some extent underpowered and the confidence intervals on many of the odds ratios are extremely wide. Due to the issues with generalisation outlined above, it is not clear how applicable the findings of the present study would be to other populations. I would expect the prevalence rates to be much lower outside of large cities. However, it would also be very interesting to see whether rates differ across cultures. The UHR state is currently being treated across the world, from Australia to North America, Western Europe and East Asia, and each service would benefit from knowing the extent to which it is currently serving the needs of its community.

11.7 Conclusion

The work presented in this thesis has been an important expansion on past efforts to investigate the UHR state in the general population. In setting out to address the problem of defining the prevalence of subjects at ultra high risk of developing psychosis in the general population, I have produced prevalence estimates which fit well with previous research: very like Kelleher et al.'s (2012d) 8% estimate for UHR in the community, higher than Perala et al.'s (2007) 3% estimate for psychotic disorder, and lower than Morgan et al.'s 18% estimate for psychotic experiences in the same area. This work has also added to current knowledge by demonstrating that at least some of those who meet UHR criteria in the community may represent a genuine clinical need. In addition, the direct comparison between community and clinical samples who have met the same criteria is the first of its kind, and has helped to shed some initial light on how these groups may differ beyond the simple act of help-seeking.

Nonetheless, this work is by no means conclusive. It is only really the first step towards understanding this population. The limitations I have discussed at every stage of this thesis should highlight that the challenges of taking on such a task are many, and should emphasise that much remains unknown about this group. What is needed now is extensive longitudinal follow-up of this sample and others like it to determine whether the UHR criteria used in this way have any power to predict the long term functional outcomes and quality of life of these individuals, or indeed to predict the development of psychosis.

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VI. APPENDICES

APPENDIX A – REVIEW OF THE PSQ

This chapter has been included in the appendix because, although it does not fit with the overall thesis, it serves as a useful reference for how the PSQ has been used and interpreted.

CHAPTER 12 INVESTIGATING PSYCHOTIC EXPERIENCES IN THE GENERAL POPULATION USING THE PSYCHOSIS SCREENING QUESTIONNAIRE – THE IMPORTANCE OF METHOD

The present chapter concerns the use of the psychosis screening questionnaire (PSQ; Bebbington and Nayani, 1995). The PSQ is an important starting point for the thesis for two main reasons: firstly, it has been used in a large general population sample within the same catchment area as the present study, and secondly, its hierarchical structure provides an illustrative example of the psychosis continuum. Here, I will describe the PSQ in detail and provides the first systematic review of its use on general population studies, bringing focus to a previously unacknowledged disagreement over how it should be used and interpreted in such a setting, and then applying the results to secondary data from the ONS Adult Psychiatric Morbidity Survey (McManus et al., 2009). This review has important implications since the method used impacts greatly on the prevalence of psychotic experiences identified and on the validity of the subsequent interpretations. The conclusions of this chapter will inform how the PSQ is used elsewhere in the thesis.

12.1 Introduction

The psychosis screening questionnaire (PSQ) was created by Bebbington and Nayani (1995) and is a structured questionnaire which assesses psychotic experiences within the last year across five domains: hypomania, thought disorder, paranoia, strange experiences and hallucinations. It is structured so that each of the five sections contains an initial probe question and one or two follow-up 'key' questions which are asked only if the probe question has already been endorsed. The probe question is designed to be vague and unthreatening, and captures a broad area of experience: for example: "Over the past year have there been times when you felt that something strange was going on?" In contrast, the key questions are intended to identify rarer forms of experience which are closer to psychotic symptoms and are

therefore more specific, for example: “Did you feel it was so strange that people would find it very hard to believe?” These key questions help to distinguish experiences that are likely to be common and part of normal experience from those which are more unusual and may be clinically relevant. The questionnaire is shown in full in Table 12.4.

The PSQ was originally designed as a screening tool that could be conducted by lay interviewers to quickly identify possible cases of psychosis. These could then be followed up in more detail using clinical assessments such as the Schedules For Clinical-Assessment In Neuropsychiatry (Wing et al., 1990). It has been validated in this way in two national surveys in the UK (Nazroo, 1997; Singleton et al., 2003). In its original use the PSQ would be discontinued as soon as a subject screened positive on any of the five domains (by endorsing all of the questions within that domain); however, the PSQ has since been included in full in a number of large-scale population studies (Das-Munshi et al., 2012; Jenkins et al., 2012, 2003; Morgan et al., 2009) in which the interviewer continued through all five domains regardless. Consequently, researchers have made use of this information and the PSQ itself has been treated as an outcome measure in several studies, providing an index of subclinical psychotic experiences. When used in this way the PSQ has produced patterns of association that seem to fit well with the findings of other psychosis studies (Morgan et al., 2009) and those endorsing symptoms have been shown to be similar to those identified using clinical measures (Johns et al., 2002). This is consistent with the concept of a phenomenological continuum for psychosis, which has underpinned much of the research into psychotic experiences in the general population (David, 2010; Linscott and van Os, 2013; van Os et al., 2009). Likewise, even among PSQ responses, the key questions (indicating experiences that are more ‘psychotic’) tend to be endorsed far less often than the probe questions (Johns et al., 2004; Morgan et al., 2009; Wiles et al., 2006). It could therefore be claimed that although the PSQ was never intended for use as a measure of subclinical psychotic experiences, it does appear to work.

Nevertheless, there does not seem to be a consensus in how the PSQ is used and reported in this type of study and this variability is potentially problematic when it comes to comparing estimates across studies. In order to address this issue, a systematic review was conducted to identify the different methods used for interpreting and reporting the PSQ throughout the literature. These methods were then applied to existing data to assess the implications of these differences. On the basis of these, recommendations are made about the use of the PSQ in future studies.

12.2 Systematic review

12.2.1 Method

An electronic literature search was conducted in February 2014. The forward citation feature in ISI Web of Science was used to produce a list of papers which cited the Psychosis Screening Questionnaire (Bebbington and Nayani, 1995). This was supplemented by a hand search of references within these articles to identify any relevant studies that had not appeared in the electronically derived list. Titles were first examined to produce a smaller list of potentially relevant papers, then the abstract and paper content were scrutinized according to the following inclusion criteria: 1) original paper published in a peer reviewed journal, 2) use of four or more domains of the PSQ. Where there were overlapping datasets papers were still included since different authors may interpret and report the PSQ results differently. The overall search strategy is shown in Figure 12.1.

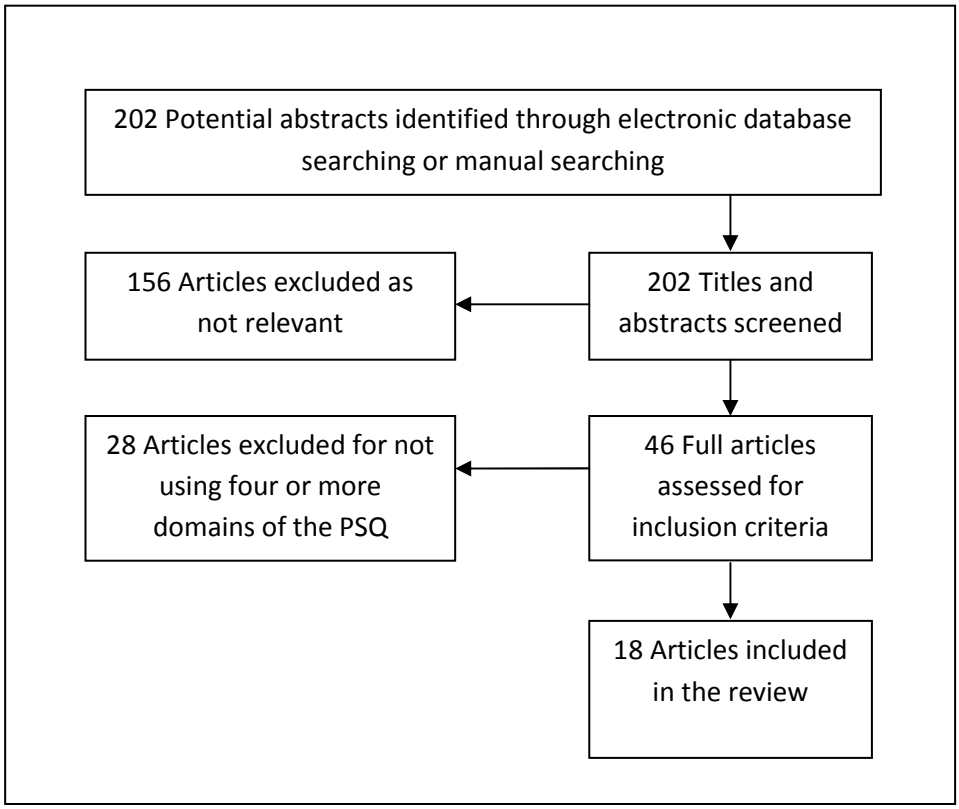


Figure 12.1. Search strategy used for the inclusion of studies in the current review.

Articles that met the inclusion criteria were then categorised according how primary outcomes were derived from the PSQ for use in the analyses. In particular, methods were scrutinised to determine which items of the PSQ had been included. In papers where this was not directly reported, authors were contacted for further details and confirmation of the items used. Secondly, papers were grouped according to the samples they examined and a prevalence rate for one or more psychotic experience(s) was sought for each sample. If this figure was not directly reported in the published material, tables were examined to see if an overall prevalence could be derived. Where the original source data was publicly available, the prevalence was calculated directly.

12.2.2 Results and Discussion

Eighteen papers met the inclusion criteria for this review (Figure 12.1). The most common reason for exclusion in the final stage was that the study did not include the PSQ among its assessments. Other excluded studies either used the PSQ as a clinical screen rather than an outcome measure, or used fewer than four domains (for example looking only at paranoia). The PSQ's inclusion in several large scale population studies meant that within this there was some overlap between the samples examined. Therefore these seventeen papers referred to ten independent samples from four different countries, predominantly the UK. The largest and most widely used of these population samples were the Office of National Statistics British National Psychiatric Morbidity Survey and its various follow ups, and the Ethnic Minorities Psychiatric Illness Rates in the Community survey. All of these studies expressly looked at an adult sample, typically specifying a lower age limit of 16 years (with the exception of the Tanzanian sample, for whom this was 15 years (Jenkins et al., 2010)) and an upper limit between 59 and 80 years.

Methods of reporting the PSQ

Five distinct methods were identified for interpreting and reporting the PSQ (see Table 12.1). Distinct methods were defined by the specific PSQ items considered in the ratings. Variations are included within these methods, where one additional item was present each time. A list of papers included is shown in Table 12.2.

Table 12.1 PSQ methods identified by items included

PSQ Items		PSQ Method				
		I	II	III	IV	V
Hypomania	*1A (probe)*				(X)	(X)
	1B					(X)
	1C (key)	X	(X)	(X)		(X)
Thought insertion	*2A (probe)*				X	X
	2B (key)	X	X	X		X
Paranoia	*3A (probe)*				X	X
	3B (key 1)		X			X
	3C (key 2)	X		X		X
Strange experiences	*4A (probe)*				X	X
	4B (key)	X	X	X		X
Hallucinations	*5A (probe)*			X	X	X
	5B (key)	X	X	(X)		X

Method I = all those responding positively to the highest level experience within any domain

Method II = as Method I but also including those who endorse the second level experience of paranoia

Method III = as Method I but also including those who endorse the initial probe for hallucinations

Method IV = all those responding positively to an initial probe question in any domain

Method V = all subjects given a continuous score derived from all PSQ items

Note: (X) denotes items subject to variation: Methods II, III, IV and V have all appeared with and without items related to hypomania, whereas Method III has appeared with and without item 5B

Table 12.2 Papers included in the systematic review, grouped by PSQ method used

PSQ Method (Source)		**Participant cohort**	**Country**
Method I			UK
1	(Coid and Ullrich, 2011)	PMAP + BPMS	UK
1	(Das-Munshi et al., 2012)	EMPIRIC	UK
1	(Jenkins et al., 2010)	AMMP	Tanzania
1	(Jenkins et al., 2012)	Maseno community sample	Kenya
1	(Johns et al., 2004)	BPMS	UK
1	(Karlsen et al., 2005)	EMPIRIC	UK
1	(King et al., 2005)	EMPIRIC	UK
1	(Murphy et al., 2013)	BPMS	UK
1	(Tarricone et al., 2009)	Romanian immigrant sample	Italy

Method II			
2	(Morgan et al., 2009)	AESOP	UK
2[a]	(Wiles et al., 2006)	BPMS follow up	UK
Method III			
3	(Murphy et al., 2012)	APMS	UK
3[a]	(Murphy et al., 2014)	APMS	UK
3[b]	(Shevlin et al., 2013)	APMS	UK
Method IV			
4	(Murphy et al., 2007)	BPMS	UK
4[a]	(Barnett et al., 2012)	NSHD	UK
Method V			
5	(Brosnan et al., 2010)	University student sample	UK
5[a]	(Jonas and Markon, 2013)	BPMS + APMS	UK

AMMP = Adult Morbidity and Mortality Project

AESOP = Aetiology and Ethnicity in Schizophrenia and Other Psychoses

BPMS = Office of National Statistics British Psychiatric Morbidity Survey, 2000

APMS = Office of National Statistics Adult Psychiatric Morbidity Survey, 2007

PMAP = Office of National Statistics Survey of Psychiatric Morbidity among Prisoners, 1997

EMPIRIC = Ethnic Minorities Psychiatric Illness Rates in the Community survey

NSHD = National Survey of Health and Development

[a] Hypomanic items excluded

[b] Includes hallucination key question in addition to probe

Method I was most in line with the original method described by Bebbington and Nayani; in order to screen positive for a symptom on the PSQ, subjects must answer 'yes' to all questions within that symptom category. In other words the highest level key questions are responsible for defining the presence of a psychotic experience. In this way Method I can be regarded as the most conservative of the five approaches. Typically, those endorsing one or more symptom(s) were regarded as having screened positive on the PSQ. However, one study reviewed increased the stringency of criteria by categorising subjects based on the presence of two or more experiences among women and three or more experiences among men (Coid and Ullrich, 2011), owing to the increased prevalence of psychotic experiences among prisoners. Within this review, Method I was the most commonly used and was found in nine of the seventeen papers. Each of the following alternative methods was found in two papers.

Method II was similar to Method I, but with the important difference that subjects need only answer 'yes' to the first key question within the paranoia category to be defined as having had a potentially psychotic experience (rather than the second key question). It can be argued that the second paranoia key question relates specifically to delusions of conspiracy, which may exclude other forms of paranoid delusion. One implication of this approach is that it identifies a greater number of individuals compared with Method I; however, this urges additional caution because of the increased likelihood of identifying and falsely including individuals whose paranoid feelings are not delusional. A variation on this method was to also disregard the hypomania category in order to focus just on the positive psychotic symptoms. This approach was used in two of the seventeen papers: (Morgan et al., 2009; Wiles et al., 2006). Morgan et al. report the PSQ results with and without hypomania. Wiles et al. exclude the hypomania items from their consideration throughout, but do additionally report PSQ prevalence using Method I for the remaining sections. The exclusion of hypomania is justified on two counts: firstly it is seen as unlike the other four positive categories because of its more affective nature, making it arguably less specific to psychosis. Secondly the response rates for the hypomanic probe have often been found to be greatly in excess of the other items (e.g. Murphy et al., 2014), bringing the whole category into question.

Method III was found in three papers. In line with Method I, the highest level key questions were considered for the first four categories. However, endorsement of the hallucinations category was assessed using the probe question. The justification for this is that the hallucination probe represents both auditory and visual hallucinations, while the key question includes just auditory hallucinations. The implication is that this may be over-specific in the experience that it identifies and could exclude individuals who are experiencing a clinically relevant psychotic experience. One paper also included the key question for hallucinations as an additional screening item (Shevlin et al., 2013); however, the hierarchical administration of the PSQ prevents this from identifying new individuals, rather it may provide additional indicators of severity. Subjects endorsing any of these items were regarded as having had a potentially clinically relevant experience. Again, one of these papers also disregarded the hypomania items (Murphy et al., 2014).

Method IV refers to the use of just the probe questions for each PSQ category, with only the endorsement of one or more probe question defined a subject as screening positive on the PSQ. This is the most liberal and inclusive of the approaches and as such is likely to identify the greatest number of 'false positives'. It is arguably then the least valid at identifying 'psychotic experiences'. Although it may be possible that the probes could represent "softest expression of an extended psychosis phenotype" (van Nierop et al., 2012, p. 231), it is also possible that

endorsement of the initial probe may have nothing to do with psychotic experiences and may be better explained by individual differences in culture or personality, or by other problems, such as anxiety. Indeed one paper using this method noted a large overlap between experiences endorsed on the PSQ and other measures of depression and anxiety, yet the authors in question do not fully acknowledge the extent of this limitation (Barnett et al., 2012). The same paper also disregarded hypomania items for the same reasons noted above.

Finally, **Method V** involved the use of al PSQ items to create a continuous scale. Although found in two papers, the authors used slightly different ways of standardizing their scales, meaning that the resultant scores are not directly comparable. Neither paper uses these PSQ scores as a primary outcome in itself, but rather the continuous scores are entered as predictors into a statistical model along with other variables. Again there was some variation in the approach to hypomania and these items were disregarded in one of the studies (Jonas and Markon, 2013). This approach has the advantage of potentially increasing statistical power by being able to examine the entire sample. Nevertheless to consider the PSQ items as a continuous score is extremely problematic given that the PSQ is designed as a hierarchical measure; all the items do not have the same weighting. For example an individual with florid hallucinations but no other symptoms would receive a score of 2, the same as an individual who endorsed two probe questions for mania and paranoia but no key questions. These individuals are equated by this method but their experiences are very different.

It is important to note that, while distinct, the five methods will identify overlapping groups of individuals. For example, an individual who endorsed all symptoms on the PSQ would be identified by each of the five methods described, along with any other individuals who endorsed the highest level experience for any of the domains (with the possible exception of hypomania, given that this was excluded from a number of studies). Methods II and III were similar in that they would identify all the individuals identified by Method I with the addition of those who endorse a lower level experience within the paranoia and hallucination domains respectively. Method IV would identify all of the above along with any individuals who responded positively to a probe question for any of the other domains. Meanwhile the entire sample would receive a continuous score using Method V.

The different definitions used by these five methods represent different assumptions about what is considered to be a psychotic experience. For the reasons outlined above, Method V can be regarded as fundamentally flawed in its approach; however, the other four methods might be conceived as identifying experiences which lie at different points along the phenomenological continuum. As a result of the PSQ's hierarchical structure, these different methods will also differ in the number of individuals they identify as reporting a psychotic

experience. While studies using Method I will identify individuals with experiences that are arguably most like psychotic symptoms, the size of this group will be smaller than it would be using other methods. Conversely, Method IV is likely to identify a much larger group, but at the cost of the specificity of the experiences identified.

Prevalence of psychotic experiences

The prevalence of psychotic experiences as measured by the PSQ varied between 3.9% and 19% across the different samples included in this review. The overall prevalence of endorsing one or more category on the PSQ is shown in Table 12.3 for each of the samples where this had been reported.[10] Prevalence showed some variation across studies, but most reported a figure of around 4-8%. This is well within the range that one might expect for psychotic experiences in general population studies (van Os et al., 2009) and seems relatively reliable given that the same assessment tool was used for all. Nevertheless, two studies reported much higher rates of around 19%. This variation can be attributed partly to the fact that the study by Tarricone et al. used a sample of Romanian immigrants who had settled in a hotel on the outskirts of Bologna and were living in extremely deprived conditions. Both migrant status and socioeconomic deprivation have been shown to be risk factors for symptoms on the psychotic continuum (Croudace et al., 2000; Lasalvia et al., 2014; van Os et al., 2009; Zammit et al., 2010). In contrast, all the other studies in Table 12.3 were representative general population samples. Secondly, the higher rate reported by Morgan et al. can be largely attributed to the different approach taken for analysing and reporting the PSQ, using Method II rather than Method I (as all the others had done). However, the AESOP sample includes a highly urban area of South London, with a high concentration of risk factors for psychosis, which may also add to the higher prevalence estimate.

The remaining cohorts in Table 12.3 were all obtained through general population sampling and share the same method for defining individuals as having screened positive on the PSQ. These samples show similar rates despite representing three different countries. However, all were sampled from relatively urban populations and used comparable age ranges.

Unfortunately the overall prevalence rates were not reported for all studies included in this review. It was therefore not possible to make a valid comparison of all the different methods. In order to achieve this, the methods would need to be applied to the same data.

[10] Other studies reported the prevalence for each of the PSQ categories individually.

Table 12.3 Prevalence of psychotic experiences as measured by the PSQ

Participant cohort, country (Source)	Prevalence
Adult Morbidity and Mortality Project (AMMP), Tanzania (Jenkins et al., 2010)	3.9%[a]
Aetiology and Ethnicity in Schizophrenia and Other Psychoses (AESOP), UK (Morgan et al., 2009)	18.6%[b]
Office of National Statistics British Psychiatric Morbidity Survey 2000 (BPMS), UK (Johns et al., 2004; Murphy et al., 2013)	6%[a]
Office of National Statistics Adult Psychiatric Morbidity Survey 2007 (APMS), UK (National Centre for Social Research and University of Leicester, 2011) [c]	5.6%[a]
Community survey from Maseno, Kenya (Jenkins et al., 2012)	8.1%[a]
Ethnic Minorities Psychiatric Illness Rates in the Community survey (EMPIRIC), UK (Das-Munshi et al., 2012)	8%[a]
Romanian Immigrant sample in Bologna, Italy (Tarricone et al., 2009)	19%[ad]

[a] Reported using Method I [b] Reported using Method II (mania included)

[c] (calculated from source data) [d] Not a representative general population sample

12.3 Applying methods to the APMS dataset

12.3.1 Method

The ONS Adult Psychiatric Morbidity Survey (APMS) data is freely available from the online UK data archive (National Centre for Social Research and University of Leicester, 2011). Details of the methods used to obtain the data are described elsewhere (McManus et al., 2009). In brief, the APMS was a general population survey conducted in the UK in 2007 (*n* = 7403), which randomly sampling households from the UK postal address file. Individuals aged 16 years and over (mea*n* = 51 years) were interviewed, focusing on their psychiatric morbidity. To complement the current review, PSQ data from the APMS was analysed using four of the five methods described above, allowing them to be compared accurately. Method V was not included in these analyses because it was incomparable with the other methods.

Comparisons were made firstly in terms of the prevalence of psychotic experiences (as defined by each approach) to examine the extent of the difference between the methods. Secondly, associations with key demographic variables were assessed to investigate any

phenomenological differences between the types of experiences identified. Ethnicity, employment and relationship status were all self-ascribed. To simplify the analyses, binary variables were created for use as predictors within logistic regression models. Levels chosen were based on the findings of previous studies, highlighting factors known to be associated with experiences on the psychosis continuum. Ethnicity was coded as black or other, unemployed status did not include individuals who were economically inactive (such as a student, retired or house person), and single status included all those not currently in a relationship (including divorced, separated and windowed individuals). Logistic regression analyses were performed on the outcome of each method separately and predictors were entered at once into the same model.

12.3.2 Results and discussion

Responses to individual items on the PSQ are shown in Table 12.4. The most common experience was the least extreme level of hypomania, endorsed by over half of the sample, followed by the probes for paranoia (18%), strange experiences (8%) and thought insertion (8%). The hallucinations probe was endorsed by less than five per cent of the sample. As in previous studies the rate of 'yes' responses was much greater for the initial probe questions than for the subsequent key questions; for example the two key questions for paranoia were endorsed by eight per cent and two per cent of the sample respectively. These response patterns are typical of those reported elsewhere (e.g. Johns et al., 2004).

Table 12.5 shows the prevalence of psychotic experiences as defined by the various approaches identified in this review. As predicted the number of individuals meeting Method IV criteria was far larger than the other groups, representing over 60% of the sample (or 24% when hypomania was not considered). The proportions of the sample identified by the other approaches were far more similar to one another: Method I was around 6%, Method II around 10% and Method III around 8%. Interestingly, the prevalence resulting from Methods II and III did not differ by even a whole percentage point between the inclusion and exclusion of the hypomania items, suggesting that this decision would make little difference to the outcomes. Likewise, the prevalence produced by the most conservative (Method I) and less conservative approaches (II and III) all fall within the expected range for psychotic experiences, supporting the idea that these approaches may be more comparable to previous work in this area than Method IV. Despite being relatively small, the differences between Methods I, II and III represent potentially important conceptual differences in terms on the strength of psychotic experience and where it might be placed along a phenomenological continuum.

Table 12.4 PSQ item response summary for APMS (*n* = 7403)

PSQ symptom categories *Initial probe* **Key questions**		'Yes' Responses n (%)	
Hypomania			
1A	*Over the past year, have there been times when you felt very happy indeed without a break for days on end?*	3816	(51.6)
1B	Was there an obvious reason for this?	2058	(27.8)
1C	**Did your relatives or friends think it was strange or complain about it?**	**44**	**(0.6)**
Thought insertion			
2A	*Over the past year, have you ever felt that your thoughts were directly interfered with or controlled by some outside force or person?*	579	(7.8)
2B	**Did this come about in a way that many people would find hard to believe, for instance through telephony?**	**77**	**(1.0)**
Paranoia			
3A	*Over the past year, have there been times when you felt that people were against you?*	1299	(17.6)
3B	**Have there been times when you felt that people were deliberately acting to harm you or your interests?**	**569**	**(7.7)**
3C	**Have there been times when you felt that a group of people was plotting to cause you serious harm or injury?**	**125**	**(1.7)**
Strange experiences			
4A	*Over the past year have there been times when you felt that something strange was going on?*	611	(8.3)
4B	**Did you feel it was so strange that people would find it very hard to believe?**	**239**	**(3.2)**
Hallucinations			
5A	*Over the past year, have been times when you heard or saw things that other people couldn't*	323	(4.4)
5B	**Did you at any time hear voices saying quite a few words or sentences when there was no-one around that might account for it?**	**68**	**(0.9)**

Note: percentages are unweighted

Table 12.5 Prevalence of psychotic experiences within the APMS as defined by various PSQ methods

	Hypomania included		Hypomania not included	
Prevalence of psychotic experiences as defined by:	n	(%)	n	(%)
Method I	415	(5.6)	-	-
Method II	768	(10.4)	740	(10.0)
Method III	584	(7.9)	557	(7.5)
Method IV *(probe questions only)*	4480	(60.7)	1748	(23.7)

Note: percentages are unweighted

A series of logistic regression analyses revealed very similar patterns of association between Methods I, II (with and without mania) and III (with and without mania) and key demographic measures, with black ethnicity, single status and unemployment all being associated with increased odds of endorsing a psychotic experience (see Figure 12.2 for odds ratios and 95% confidence intervals). For Methods I-III, single status was most strongly associated with reporting a psychotic experience (OR range = 1.72 to 2.05), followed by unemployment (OR range = 1.60 to 1.90) and black ethnicity (OR range = 1.43 to 1.87). The odds of reporting a psychotic experience slightly decreased with age but the impact of this association was negligible (all ORs = 0.98). No evidence was found for an association with sex. In contrast, psychotic experiences as defined by Method IV (mania included) showed an identical association with age (OR = 0.98) but no evidence for any other associations. When the mania items were disregarded, Method IV revealed weaker associations with unemployment (OR = 1.45) and single status (OR = 1.42), but insufficient evidence for an association with sex or ethnicity.

It would appear then that the distinction between the most conservative and the slightly less conservative approaches is by no means fundamental. All of these approaches show similar patterns of association as a result of identifying many of the same individuals. Likewise, these approaches replicate the associations found in other studies of clinical psychosis and psychotic experiences, supporting the idea that these measures are tapping into experiences that lie along this continuum. Meanwhile, the differences shown between Method IV and the other approaches leads to the opposite conclusion: that using the probe questions alone does not result in the measurement of the same construct, at least not when the hypomania probe is included. This highlights the validity of the distinction between the probe questions and the key questions within the PSQ in relation to psychotic experiences. The increased odds associated with being single, Black or unemployed simply do not apply when all the probe

questions are considered. The hypomania items appear to be largely responsible for this, since the associations with being single or unemployed return when hypomania is disregarded.

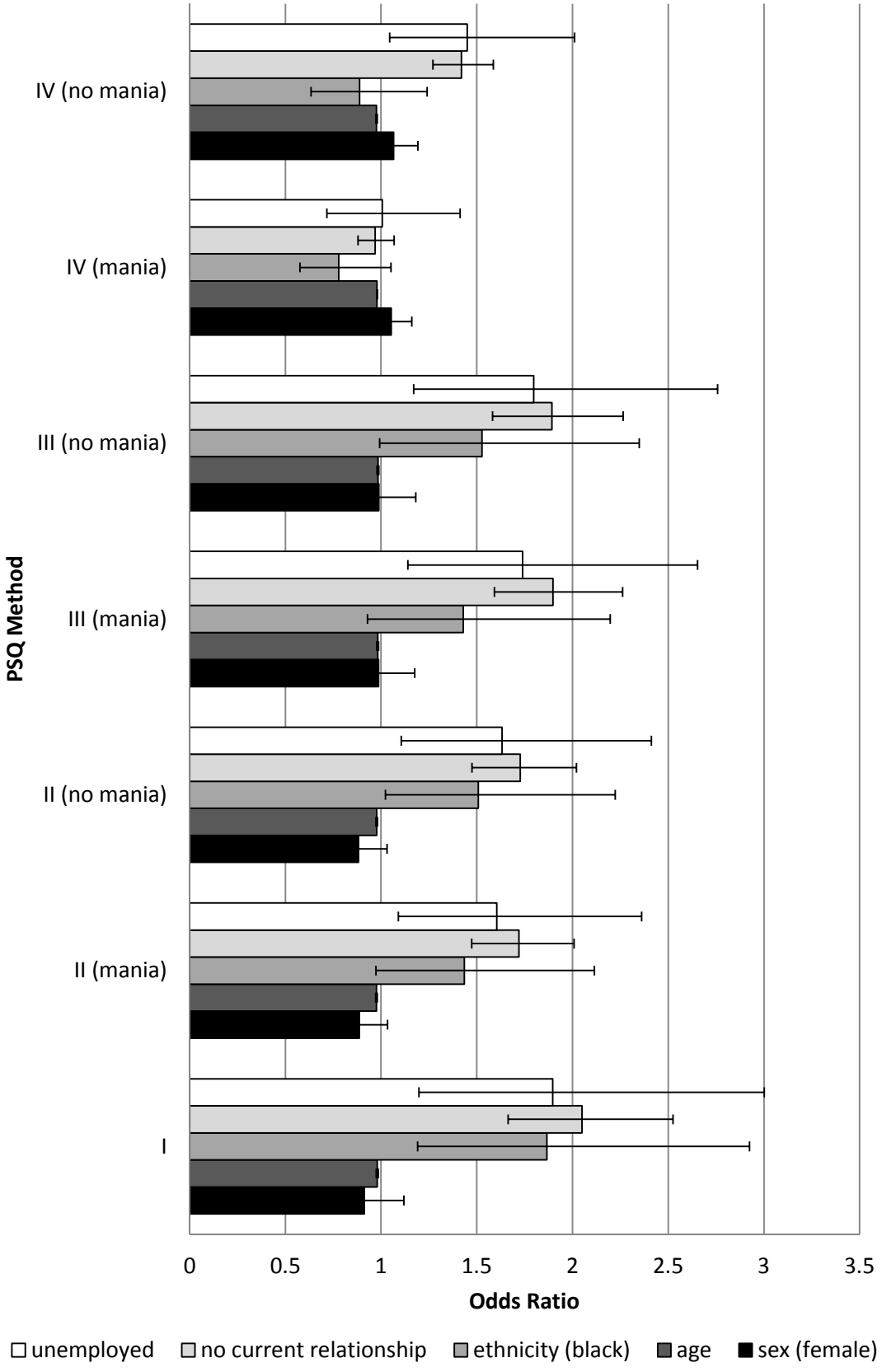


Figure 12.2 Associations between PSQ and basic demographics for different PSQ methods

Nevertheless the association between psychotic experiences and ethnicity is not seen when Method IV is used, representing a key difference in the type of experience that is measured. It is possible that these experiences are more associated with other common mental disorders such as anxiety, which do not share the same associations as psychosis, but it is also possible that these are far more a part of normal experience throughout the population. These items are also more ambiguous and so may be misinterpreted more often than the key questions, which relate more specifically to psychotic experiences.

12.4 Conclusions

This chapter has identified the need for a review of how the PSQ has been used and interpreted in the literature to date. The review itself has identified five distinct approaches, along with several variations. The findings of the review have then been applied to existing data in order to explore these different approaches further. All that remains now is to draw some conclusions and make some recommendations.

Firstly, for studies whose aim is to identify experiences most like those found in psychotic disorder, it seems clear that Method I should be viewed as the standard approach to take with the PSQ. The majority of papers included in the review used Method I for interpreting the PSQ and in many ways this seems most appropriate, given its similarity to the original design of the tool and to the form in which the PSQ was validated. Moreover, it is the method used in all papers that include Paul Bebbington, one of the tool's co-creators, among its authors. Use of just the key questions increases the likelihood of identifying 'genuine' psychotic experiences rather than 'false positives'. Future studies should be aware of this when deciding which method to use.

In contrast, the validity of Methods IV and V is highly questionable. The use of just the probe questions in Method IV appears to be too liberal an approach, including well over half of the sample and not replicating the associations displayed by other methods. While this approach could be used to loosely describe some kinds of experiences reported by a sample, it is too great a step to refer to these as being on the psychosis continuum with any confidence. The experiences explored in the probe questions are likely to occur in a wider range of contexts, such as anxiety or insomnia, and less likely to be psychotic in nature than those identified by the key questions. Meanwhile, to give equal value to each item on the PSQ, as Method V does, is to ignore the hierarchical structure which is integral to its interpretation.

Methods II and III are less problematic. The applied part of this review revealed that the numbers of individuals identified by these methods were greater but not too dissimilar from

those identified by Method I. Likewise the associations identified with basic demographic variables were also very similar, particularly for Method II. Method II also assumes a level of equivalence between the key questions, identifying individuals on the basis of a positive response to any of these and treating the additional key question for paranoia as an anomaly. Consequently, it will identify individuals with weaker but still potentially relevant experiences of paranoia. For example, if an individual has some feelings of paranoia, item 3A on the PSQ identifies the generalising and externalising of this perceived threat, which could be considered a psychotic experience in itself and would be included in Method II without requiring the endorsement of item 3B, which identifies a more specific threat. Meanwhile, studies which aim to look at hallucinations in a broader sense could be justified in using Method III to approach the PSQ, so as not to exclude any individuals who may have visual rather than just auditory experiences.

Since the questions of the PSQ may be misinterpreted or misunderstood by subjects, and because there is some ambiguity inherent in the questions themselves, there is always likely to be some misclassification when it comes to identifying psychotic experiences. Therefore there will be some tension present between 'false positives' and 'false negatives', the balance of which is determined by the method chosen. Moreover, there is evidence to suggest that so called false positives may show many of the same associations (for example with trauma) as subjects with confirmed psychotic symptoms (Bak et al., 2003a; van Nierop et al., 2012). On the basis of this, some studies may wish to use these slightly more relaxed criteria to be more inclusive in terms of the kinds of experiences identified. In order to do this though, this decision needs to be explicit.

The clear justification of the method used, along with whether and why it differs from the approach taken by other researchers, is something that is missing from all of the papers reviewed in this chapter. Yet the choice of method for each paper presumably did not occur at random; it is more likely that the authors were not aware that there was a choice at all. This stems from a lack of acknowledgement in the literature that the PSQ has been (and is being) used opportunistically and interpreted in a number of different ways across studies, and it is a hope of this author that this review may help to change this. It is the recommendation of this author therefore that acknowledgement of this should become commonplace among future publications which attempt to use the PSQ in this way.

In summary, future research should pay careful attention to how the PSQ is used and reported. It is important to firstly acknowledge that the PSQ has been used opportunistically for a purpose it was never designed for. This review has shown that whilst the use of just the probe questions as an index of psychotic experiences should be avoided, methods which

include the key questions are likely to identify experiences at varying points along the psychosis continuum. Studies wishing to be more inclusive of weaker experiences of paranoia or hallucinations may be justified in doing so provided that it fits with the aims of their study. Nevertheless, it is vital for researchers to recognise, understand and be explicit about the implications of their chosen method.

APPENDIX B – MEASURES

Schizotypal Personality Disorder (items from the SCID-II)

A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships as well as by cognitive or perceptual distortions and eccentricities of behaviour, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

(1) Ideas of reference, i.e., not convinced that this is happening (excluding delusions of reference).
(2) Odd beliefs or magical thinking that influences behaviour and is inconsistent with subcultural norms (e.g., superstitiousness, belief in clairvoyance, telepathy, or "6th sense", in children and adolescents, bizarre fantasies or preoccupations).
(3) Unusual perceptual experiences including bodily illusions.
(4) **Observed:** Odd thinking and speech (e.g., vague, circumstantial, metaphorical, over-elaborate, or stereotyped).
(5) **Observed:** Inappropriate or restricted affect.
(6) **Observed:** Behaviour or appearance that is odd, eccentric, or peculiar.
(7) **Observed:** Suspiciousness or paranoid ideation.
(8) Lack of close friends or confidants other than first degree relatives.
(9) Excessive social anxiety that does not diminish with familiarity and tends to be associated with paranoid fears rather than negative judgements about self.

Scoring for each item:

1 = absent or false 2 = subthreshold 3 = threshold or true

See SCID-II (First et al., 1997) for details.

SUBJECT NUMBER _____

1: POSITIVE SYMPTOMS

1.1 UNUSUAL THOUGHT CONTENT

Delusional Mood and Perplexity ('Non Crystallized Ideas')

- Have you had the feeling that something odd is going on that you can't explain? What is it like?
- Do you feel puzzled by anything? Do familiar surroundings feel strange?
- Do you feel that you have changed in some way?
- Do you feel that others, or the world, have changed in some way?

(Unstable) Ideas of Reference

o Do you sometimes relate what happens around you to yourself, e.g. actions or comments by others, although you know at once that this is not true?

o Do you sometimes feel that things going on around you have a special meaning for you, even though you know at the same time that this is improbable or impossible?

o Do you sometimes feel as if random things were meant especially for you, e. g. comments on the radio or TV? What does it take for you to realise that this is just a sudden idea and not true? How long does this idea last?

Have you felt that things that were happening around you had a special meaning, or that people were trying to give you messages?

- What is it like? How did it start?

Bizarre Ideas ('Crystallized Ideas')

- <u>Made thoughts, feelings, impulses</u>: Have you felt that someone, or something, outside yourself has been controlling your thoughts, feelings, actions or urges? Have you had feelings or impulses that don't seem to come from yourself?

o <u>Thought interference:</u> Are you ever bothered by thoughts that appear in your mind, but are not related to anything you are doing or thinking about?

If you want to concentrate on a book, movie, conversation or work, does it happen that your concentration suddenly gets disturbed by unimportant, unrelated thoughts?

Do you sometimes find it difficult to take part in a conversation, because unimportant and unrelated thoughts enter your mind?

What are these intruding thoughts or images like? Do they have a special emotional meaning for you, or are they just meaningless and emotionally irrelevant?

- <u>Somatic Passivity</u>: Do you get any strange sensations in your body? Do you know what causes them? Could it be due to other people or forces outside yourself?

- Thought Insertion: Have you felt that ideas or thoughts that are not your own have been put into your head? How do you know they are not your own? Where do they come from?

o Thought blockages: Do you sometimes lose your train of thought? Do your thoughts suddenly disappear as if they were cut short?

Do your thoughts suddenly stop sometimes, as if they are being blocked or as if the thought gradually fades? Does another thought take the place of the old one?

- Thought Withdrawal: Have you ever felt that ideas or thoughts are being taken out of your head? How does that happen?

- Thought Broadcasting: Are your thoughts broadcast so that other people know what you are thinking?

o Thought pressure: Do you sometimes have the feeling that you were not able to control your thoughts anymore? That your thoughts would just run wild?

Do you sometimes jump from one subject to another so much that the single thoughts are actually unrelated to each other?

Do you sometimes find it difficult to control your thoughts- so that several different thoughts enter your mind at the same time? Is it difficult to stop other new thoughts coming into your mind as well?

Do you think about one new idea after another? Do these thoughts whirl about in your mind? Are these thoughts impossible to control?

- Thoughts Being Read: Can other people read your mind?

UNUSUAL THOUGHT CONTENT- GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic and Severe**
No unusual thought content.	Mild elaboration of conventional beliefs as held by a proportion of the population	Vague sense that something is different, or not quite right with the world, a sense that things have changed but not able to be clearly articulated. Subject not concerned/ worried about this experience.	A feeling of perplexity. A stronger sense of uncertainty regarding thoughts than 2.	Referential ideas that certain events, objects or people have a particular and unusual significance. Feeling that experience may be coming from outside the self. Belief not held with conviction, subject able to question. Does not result in change in behaviour.	Unusual thoughts that contain completely original and highly improbable material. Subject can doubt (not held with delusional conviction), or which the subject does not believe all the time. May result in some change in behaviour, but minor.	Unusual thoughts containing original and highly improbable material held with delusional conviction (no doubt). May have marked impact on behaviour.

Onset date: _____ ***Offset date*:** _____

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use

Level of Distress (In Relation to Symptoms)

0 **100**
Not At All Distressed Extremely Distressed

1.2 NON-BIZARRE IDEAS

Non-Bizarre Ideas ('Crystallized Ideas')

- Suspiciousness, Persecutory Ideas: Has anybody been giving you a hard time or trying to hurt you? Do you feel like people have been talking about you, laughing at you, or watching you? What is it like? How do you know this?
- Grandiose Ideas: Have you been feeling that you are especially important in some way, or that you have powers to do things that other people can't do?
- Somatic Ideas: Have you had the feeling that something odd is going on with your body that you can't explain? What is it like? Do you feel that your body has changed in some way, or that there is a problem with your body shape?
- Ideas of Guilt: Do you feel you deserve punishment for anything you have done wrong?
- Nihilistic Ideas: Have you ever felt that you, or a part of you, did not exist, or was dead? Do you ever feel that the world does not exist?
- Jealous Ideas: Are you a jealous person? Do you worry about relationships that your spouse/girlfriend/boyfriend has with other people?
- Religious Ideas: Are you very religious? Have you had any religious experiences?
- Erotomanic Ideas: Is anyone in love with you? Who? How do you know this? Do you return his/her feelings?

NON-BIZARRE IDEAS - GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic and Severe**
No non-bizarre ideas.	Subtle changes that could be reality based. Eg. Very self-conscious.	Increased self-consciousness. Eg. Feeling that others look at the subject, or talk about the subject. Or feeling of increased self-importance. Subject able to question.	Odd or unusual thoughts but whose content is not entirely implausible- may be some logical evidence. More evidence than rating of 4. Content of thoughts not original i.e. jealousy, mild paranoia.	Clearly idiosyncratic beliefs, which although 'possible' have arisen without logical evidence. Less evidence than rating of 3. Eg. Thoughts that others wish the subject harm, which can be easily dismissed. Thoughts of having special powers, which can be easily dismissed.	Unusual thoughts about which there is some doubt (not held with delusional conviction), or which the subject does not believe all the time. May result in some change in behaviour, but minor.	Unusual thoughts containing original and highly improbable material held with delusional conviction (no doubt). May have marked impact on behaviour.

Onset date: _____ ***Offset date*:** _____

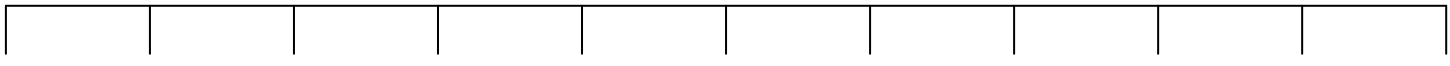
Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week **– less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use

Level of Distress (In Relation to Symptoms)



0 **100**

Not At All Distressed Extremely Distressed

1.3 PERCEPTUAL ABNORMALITIES

Visual Changes

- Distortions, illusions: Is there a change in the way things look to you? Do things somehow look different, or abnormal? Are there alterations in colour, or brightness of objects (things seeming brighter, or duller in colour)? Are there alterations in the size and shape of objects? Do things seem to be moving?
- Hallucinations: Do you have visions, or see things that may not really be there? Do you ever see things that others can't, or don't seem to? What do you see? At the time that you see these things, how real do they seem? Do you realise they are not real at the time, or only later?

o Captivation of attention by details of visual field:
Is your attention sometimes caught by a detail of your environment, and you have to look at it without wanting to?
Does a certain aspect of your surrounding sometimes stand out and seem somehow isolated from the rest?
Do you sometimes have to stare at a certain, suddenly very prominent object of your environment without intending to?

Auditory Changes

- Distortions, illusions: Is there any change in the way things sound to you? Do things somehow sound different, or abnormal? Does your hearing seem more acute, or have increased sensitivity? Muted, or less acute?
- Hallucinations: Do you ever hear things that may not really be there? Do you ever hear things that other people seem not to (such as sounds or voices)? What do you hear? At the time you hear these things, how real do they seem? Do you realise they are not real at the time, or only later?

Olfactory Changes

- Distortions, illusions: Does your sense of smell seem to be different, such as more, or less intense, than usual?
- Hallucinations: Do you ever smell things that other people don't notice? At the time, do these smells seem real? Do you realise they are not real at the time, or only later?

Gustatory Changes

- Distortions, illusions: Does your sense of taste seem to be different, such as more, or less intense, than usual?
- Hallucinations: Do you ever get any odd tastes in your mouth? At the time that you taste these things, how real do they seem? Do you realise they are not real at the time, or only later?

Tactile Changes

- Distortions, illusions, hallucinations: Do you ever get strange feelings on, or just beneath, your skin? At the time that you feel these things, how real do they seem? Do you realise they are not real at the time, or only later?

Somatic Changes

NOTE: Probes also used to rate Impaired Bodily Sensation, p.26

- Distortions, illusions: Do you ever get strange feelings in your body (eg feel that parts of your body have changed in some way, or that things are working differently)? Do you feel/think that there is a problem with some part, or all of your body, i.e. that it looks different to others, or is different in some way? How real does this seem?
- Hallucinations: Have you noticed any change in your bodily sensations, such as increased, or reduced intensity? Or unusual bodily sensations such as pulling feelings, aches, burning, numbness, vibrations?

PERCEPTUAL ABNORMALITIES - GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Psychotic but not severe**	6 **Psychotic and severe**
No abnormal perceptual experience.		Heightened, or dulled perceptions, distortions, illusions (eg lights/ shadows). Not particularly distressing. Hypnogogic/ hypnopompic experiences	More puzzling experiences: more intense/vivid distortions/ illusions, indistinct murmuring, etc. Subject unsure of nature of experiences. Able to dismiss. Not distressing. Derealisation/ depersonalis[n]	Much clearer experiences than 3 such as name being called, hearing phone ringing etc, but may be fleeting/ transient. Able to give plausible explanation for experience. May be associated with mild distress.	True hallucinations i.e. hearing voices or conversation, feeling something touching body. Subject able to question experience with effort. May be frightening or associated with some distress.	True hallucinations which the subject believes are true at the time of, and after, experiencing them. May be very distressing

Onset date: _____ ***Offset date*****:** _____

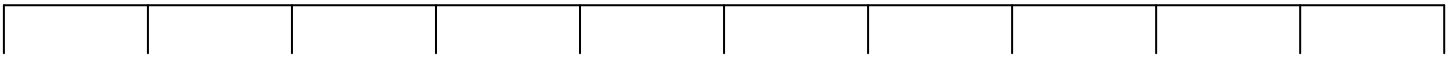
Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week **– less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use

Level of Distress (In Relation to Symptoms)



0 **100**

Not At All Distressed Extremely Distressed

1.4 DISORGANISED SPEECH

NOTE: Probes also used to rate Alogia, p. 16

Subjective Change:

o Disturbance of expressive speech: Can you still express yourself as well and precisely *as you used to*? Do you have the feeling that you can't speak as fluently and precisely as before, that sometimes it is difficult to find the right words or build the right sentences? Have you begun to use the same words and phrases again and again to avoid these difficulties?

Do you sometimes have the impression that you have difficulty expressing yourself verbally or that you don't answer the question properly?

Do you notice any difficulties with your speech, or ability to communicate with others?

Do you have trouble finding the correct word at the appropriate time?

Do you ever use words that are not quite right, or totally irrelevant?

- Have you found yourself going off on tangents when speaking and never getting to the point? Is this a recent change?
- Are you aware that you are talking about irrelevant things, or going off the track?
- Do other people ever seem to have difficulty in understanding what you are trying to say/trouble getting your message across?
- Do you ever find yourself repeating the words of others?
- Do you ever have to use gesture or mime to communicate due to trouble getting your message across? How bad is this?
- Does it ever make you want to stay silent and not say anything?

o Disturbance of receptive speech: Do you sometimes have difficulties understanding conversation or when reading simple books or articles? Were you aware of that before you started to feel unwell? (disturbance of receptive speech)

Can you understand conversations or movies as well as you used to?

Is it sometimes difficult to understand simple words or sentences? Is it as if you were reading or hearing something in a foreign, though well known language: you recognise the word but have to think about its meaning.

Nowadays, would you have to read an article or a novel more slowly, repeatedly or out loud to understand it properly?

o Disturbances of abstract thinking: Has your ability to understand and use abstract phrases decreased? For example….

Do you still always and fully understand the meaning of

metaphors or abstract things like a saying, or a proverb?

Do you sometimes misunderstand others or wonder about them, because you take what they say literally and don't recognise that it was just a saying? E.g. you ask someone, if he thinks the train would arrive in time and he answers: Pigs might fly! and you wonder what pigs have to do with trains.

Do you rather think or talk in a precise way nowadays, so that you prefer not to talk about more abstract things?

o Inability to divide attention: Can you do two things at the same time as easily as before?

Are you sometimes unable to do two different things at the same time, for example to listen and take notes while talking to someone on the telephone? Or doing some house work like cooking, tidying or washing up and talking to someone? While driving a car, can you pay attention to the traffic and listen to the radio?

Do you try to avoid situations where you have to do more than one thing at the same time?

Objective Rating of Disorganised Speech

- Is it difficult to follow what the subject is saying at times due to using incorrect words, being circumstantial or tangential?
- Is the subject vague, overly abstract or concrete? Can responses be condensed?
- Do they go off the subject often and get lost in their words? Do they appear to have difficulty finding the right words?
- Do they repeat words that you have used or adopt strange words (or 'non-words') in the course of regular conversation?

DISORGANISED SPEECH- GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic**
Normal logical speech, no disorganisation, no problems communicating or being understood.		Slight subjective difficulties eg problems getting message across. Not noticeable by others.	Somewhat vague, some evidence of circumstantiality, or irrelevance in speech. Feeling of not being understood.	Clear evidence of mild disconnected speech and thought patterns. Links between ideas rather tangential. Increased feeling of frustration in conversation.	Marked circumstantiality, or tangentiality in speech, but responds to structuring in interview. May have to resort to gesture, or mime to communicate.	Lack of coherence, unintelligible speech, significant difficulty following line of thought. Loose associations in speech.

Onset date: _____ ***Offset date*****:** _____

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week **– less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use

Level of Distress (In Relation to Symptoms)

0 **100**

Not At All Distressed Extremely Distressed

8: INCLUSION CRITERIA

INTAKE CRITERIA CHECKLIST

Group 1: Vulnerability Group

This criterion identifies young people at risk of psychosis due to the combination of a trait risk factor and a significant deterioration in mental state and/or functioning

	YES	NO
• **Family history of psychosis** in first degree relative **OR Schizotypal Personality Disorder** in identified patient	☐	☐
PLUS		
• **30% drop in SOFAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR SOFAS score of 50 or less** for past 12 months or longer	☐	☐
CRITERION MET FOR GROUP 1 – Vulnerability Group	☐	☐

Group 2: Attenuated Psychosis Group

This criterion identifies young people at risk of psychosis due to a subthreshold psychotic syndrome. That is, they have symptoms which do not reach threshold levels for psychosis due to subthreshold intensity (the symptoms are not severe enough) or they have psychotic symptoms but at a subthreshold frequency (the symptoms do not occur often enough).

	YES	NO
2a) Subthreshold intensity:		
• **Global Rating Scale Score of 3-5** on *Unusual Thought Content* subscale, **3-5** on *Non-Bizarre Ideas* subscale, **3-4** on *Perceptual Abnormalities* subscale **and/or 4-5** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of 3-6** on *Unusual Thought Content, Non-Bizarre Ideas*, *Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS for **at least a week** • **OR Frequency Scale Score of 2** on *Unusual Thought Content, Non-Bizarre Ideas*, *Perceptual Abnormalities* and *Disorganised Speech* subscales of the CAARMS **on more than two occasions (experienced a minimum of four times in total)**	☐	☐
2b) Subthreshold frequency:		
• **Global Rating Scale Score of 6** on *Unusual Thought Conten*t, **6** on Non-Bizarre Ideas, **5-6** on *Perceptual Abnormalities* **and/or 6** on *Disorganised Speech* subscales of the CAARMS		
PLUS		
• **Frequency Scale Score of 3** on *Unusual Thought Content*, *Non-Bizarre Ideas*, *Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS (for both categories)		
• **Symptoms present in past year**	☐	☐
PLUS (for both categories)		
• **30% drop in SOFAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR SOFAS score of 50 or less** for past 12 months or longer	☐	☐
CRITERION MET FOR GROUP 2 – Attenuated Psychosis Group	☐	☐

Group 3: BLIPS Group

This criterion identifies young people at risk of psychosis due to a recent history of frank psychotic symptoms that resolved spontaneously (without antipsychotic medication) within one week.

	YES	NO
• **Global Rating Scale Score of 6** on *Unusual Thought Content* subscale, **6** on *Non-Bizarre Ideas*, **5 or 6** on *Perceptual Abnormalities* subscale **and/or 6** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of 4-6** on *Unusual Thought Content*, *Non-Bizarre Ideas*, *Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales	☐	☐
PLUS		
• **Each episode of symptoms is present for less than one week** and symptoms spontaneously remit on every occasion.	☐	☐
PLUS		
• **Symptoms occurred during last year**	☐	☐
PLUS		
• **30% drop in SOFAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR SOFAS score of 50 or less** for past 12 months or longer	☐	☐
CRITERION MET FOR GROUP 3 – BLIPS Group	☐	☐

9: PSYCHOSIS THRESHOLD /ANTI-PSYCHOTIC TREATMENT THRESHOLD

	YES	NO
• **Severity Scale Score of 6** on *Unusual Thought Content* subscale, **6** on *Non-Bizarre Ideas*, **5 or 6** on *Perceptual Abnormalities* subscale **and/or 6** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of greater than or equal to 4** on *Unusual Thought Content*, *Non-Bizarre Ideas, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales	☐	☐
PLUS		
• Symptoms present for **longer than one week**	☐	☐
PSYCHOSIS THRESHOLD CRITERION MET	☐	☐

10: STUDY WITHDRAWAL ('BREAK BLIND') THRESHOLD

	YES	NO
• **Severity Scales Score of 5 or above** on *Aggression/Dangerous Behaviour* **and/or** *Suicidality/Self Harm* Subscales • **NOTE:** This should be considered independently from level of psychosis	☐	☐
STUDY WITHDRAWAL THRESHOLD CRITERION MET	☐	☐

C.1.17.	Unstable ideas of reference	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.1.1.	Thought interferences	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.1.4.	Thought blockages	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.1.3.	Thought pressure	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.2.9.	Captivation of attention by details of the visual field	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.1.7.	Disturbance of expressive speech	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C.1.6.	Disturbance of receptive speech	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
C1.16.	Disturbances in abstract thinking	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]
A.8.4.	Inability to divide attention	0 1 2 3 4 5 6	
		Score at least 3 [ ]	Present in past 3 months [ ]

AT LEAST 2 ITEMS PRESENT IN PAST 3 MONTHS WITH SCORE AT LEAST 3: **Yes [ ]**
No [ ]

Frequency ratings:

0 = never

1 = less than once in a week

2 = once in a week

3 = several times a week

4 = rather daily, longer periods of improvement possible (one to several days)

5 = daily, short periods of improvement possible (up to 24 h)

6 = daily and persistent

Contents

The shortened WAIS consists of the following subtests:

i. Digit Symbol – Coding (complete)
ii. Arithmetic (odd items only)
iii. Block Design (odd items only)
iv. Information (every third item)

Administration instructions

i. Digit Symbol – Coding

Administer according to standard procedures in the WAIS-III manual.

ii. Arithmetic

Administration begins with item 5 and continues with every other item (i.,e., 5,7,9, 11, 13, 15, 17. 19). If perfect score is obtained on item 5, the subtest score is determined as follows: (a) sum points on items 5 through 19; (b) multiply this sum by 2; and (c) add 4 points for items I through 4 that were not administered. If item 5 is failed, establish a basal in the usual was by administering items 1 through 4 in reverse order until two consecutive passes are obtained. Substitute the number of points earned on the basal items into step (c), if less than 4. Discontinue after two consecutive failures.

iii. Block Design

Administration begins with item 5 and continues with every other item (i.e, .5, 7, 9, 11, 13). If perfect score is obtained on item 5, the subtest score is determined as follows: (a) sum points on items 5 through 13; (b) multiply this sum by 2; and (c) add 8 points for items 1 through 4 that were not administered. If item 5 is either 0 or 1, establish a basal in the usual way by administering items 1 through 4 in reverse order until two consecutive scores of 2 are obtained. Substitute the number of points earned on the basal items into step (c), if less than 8. Discontinue after 2 consecutive failures.

iv. Information

Administration begins with item 6 and continues with every 3rd item (6,9,12,15,18,21,24,27). If perfect score is obtained on item 6, the subtest score is determined as follows: (a) sum points on items 6 through 27; (b) multiply this sum by 3; and (c) add 4 points for items 1 through 4 that were not administered. If item 6 is failed, establish a basal in the usual way by administering items 1 through 4 in reverse order until two consecutive passes are obtained. Substitute the number of points earned on the basal items into step (c), if less than 4. Discontinue after 2 consecutive failures.

Scoring instructions

To estimate the IQ:

1. Calculate raw scores
2. Transform into scales scores (per subtest), considering age.
3. Calculate sum score of the 4 scaled scores.
4. Sum score * 11/4 (=2.75) => WAIS estimation Total score
5. Transform into IQ-estimate

APPENDIX C – EFFECT SIZES

Certain effect sizes were calculated by hand. The following formulae were used.

1) Calculating Cramer's V (ϕ_c) for Chi-squared tests:

$$V = \sqrt{\frac{\chi^2}{n(k-1)}}$$

Where *k* is the number of rows or columns in the cross-tabulation (whichever is smaller).

2) Calculating *r* for *t*-tests:

$$r = \sqrt{\frac{t^2}{t^2 + df}}$$

3) Calculating *r* for Mann-Whitney *U* tests:

$$r = \left| \frac{z}{\sqrt{n_1 + n_2}} \right|$$

APPENDIX D – RESULTS

Reasons for not seeking help

Table D.1 Categorisation of reasons for not seeking help

Category	Responses
Practical barriers	- Did not have time because of work or other commitments such as care for children or other dependents? - Could not get transportation or your transportation was unreliable? - Have not been able to get an appointment? - *They were supposed to call back but didn't*
Negative attitudes	- Have had – or know people who have had – negative experiences seeking professional care for these kinds of problems? - Do not trust your doctor? - Felt your Doctor does not listen?
Lack of awareness	- Felt the problem would resolve on its own / Didn't think it was that serious / Didn't want to waste anyone's time? - Associate your GP with physical problems, not emotional ones?
Personal reasons / anxiety	- Did not feel comfortable / Get nervous seeing the GP? - Prefer to deal with things on your own? - Did not want to take medication / Did not want to go to hospital? - *Didn't want to go*
Fear of stigma	- Didn't want to tell anyone as you were concerned people might pass judgment on you for having these problems?

Note: responses are chosen from a list, other than those in italics, which were open-ended reponses.

Table D.2 First generation migrants (*n* = 70) by place of birth:

	EUROPE (23)	AFRICA (24)	ASIA (8)	NORTH AMERICA (9)	SOUTH AMERICA (4)	AUSTRALASIA (2)
	GERMANY (3)	NIGERIA (10)	CHINA (2)	JAMAICA (4)	CHILE (2)	AUSTRALIA (2)
	ITALY (3)	SOUTH AFRICA (3)	HONG KONG (1)	CANADA (3)	COLUMBIA (1)	
	SPAIN (3)	UGANDA (3)	INDIA (1)	ST LUCIA (1)	GUYANA (1)	
	FRANCE (2)	IVORY COAST (2)	PAKISTAN (1)	USA (1)		
	IRELAND (2)	MAURITIUS (2)	PHILLIPPINES (1)			
	POLAND (2)	CAMEROON (1)	SYRIA (1)			
	BELGIUM (1)	COMOROS ISLANDS (1)	THAILAND (1)			
	ESTONIA (1)	GHANA (1)				
	FINLAND (1)	ZIMBABWE (1)				
	HOLLAND (1)					
	HUNGARY (1)					
	LITHUANIA (1)					
	SLOVAKIA (1)					
	USSR (1)					
UHR status:	6	2	1	2	1	0